Environmental Scan Report

Integrating Patient-Generated Digital Health Data into Electronic Health Records in Ambulatory Care Settings: An Environmental Scan

Prepared for:
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

Contract No. 75Q80120D00019

Prepared by:
Ryan J. Shaw, Ph.D., R.N. [1,2]
Mina Boazak, M.D. [3]
Victoria Tiase, Ph.D., R.N. [4]
Gloria Porter, M.S.N., R.N. [2]
Jedrek Wosik, M.D. [5]
Sarah Bumatay [6]
LeAnn Michaels [6]
Julie Stone, M.P.A. [7]
Deborah Cohen, Ph.D. [8]
Rowena Dolor, M.D., M.H.S. [9,10]

1 Duke Mobile App Gateway, Clinical & Translational Science Institute, Duke University School of Medicine, Durham, NC
2 Duke University School of Nursing, Durham, NC
3 Department of Psychiatry and Behavioral Sciences, Duke University School of Medicine, Durham, NC
4 The Value Institute, New York-Presbyterian Hospital, New York, NY
5 Division of Cardiology, Department of Medicine, Duke University School of Medicine, Durham, NC
6 Oregon Rural Practice-based Research Network, Oregon Health & Science University, Portland, OR
7 OCHIN, Portland, OR
8 Department of Family Medicine, Oregon Health & Science University, Portland, OR
9 Duke Primary Care Research Consortium, Duke Clinical & Translational Science Institute, Durham, NC
10 Department of Medicine, Duke University School of Medicine, Durham, NC

AHRQ Publication No. 21-0031 May 2021

Acknowledgments
We thank Leila Ledbetter, M.L.I.S., for her expertise and assistance with library services and Martha Snow, M.P.H., for overall project management.
We thank members of the Technical Expert Panel:

Steven Kassakian, M.D., M.S., F.A.C.P., Oregon Health & Science University
Richelle Koopman, M.D., M.S., University of Missouri
James McCormack, Ph.D., Oregon Health & Science University
James Pantelas, Patient partner, Michigan
Matthew Roman, D.P.T., Duke Health
Victoria Tiase, PhD, R.N.-B.C., New York-Presbyterian Hospital

Contents

Executive Summary 5
Chapter 1. Background, Purpose 7
Chapter 2. Methods and Approach 9
  Scoping Review 9
  EHR Vendor Survey and Interview 9
  Reports, Guides, and Policy 10
  Technical Expert Panel (TEP) 10
Chapter 3. Results 11
  Scoping Review 11
  Thematic Analysis 12
  Exemplars from the Literature 16
  Guides, Reports, and Resources on the Integration of PGHD into EHRs 18
  EHR Vendor Survey and Interviews 21
  Policy, Regulation, and Reimbursement 26
Chapter 4. Summary of Results 28
  Scoping Review – the Evidence 28
  Best Practices 29
  Concerning Gaps 30
  EHR Vendor Survey and Interviews 30
  Reports, Guides, and Policies 31
  Recommendations 31
Chapter 5. Discussion 33
  The Rise of Health at Home 33
  COVID-19 and the Rise of Telehealth 34
  PGHD and Ambulatory Care 35
  Semantic Interoperability 35
  Security and Privacy 35
  Health Equity and Health Disparities 36
  Limitations 37
  Future Trends 37
Conclusion 38
References 39

Tables

Table 1. Summary of study characteristics and thematic organization (N=36) 14
Table 2. Summary of biometric data and hardware utilized to measure 15
Table 3. Summary of content integration 16
Table 4. Guides and reports related to PGHD 19
Table 5. EHR vendor survey responses (N=6) 22
Table 6. EHR vendor interview themes 23
Table 7. Recommendations for the implementation of PGHD into EHRs 31

Figures

Figure 1. Flow diagram for study selection process 11

Appendixes

Appendix A. Environmental Scan Search Terms......46
Appendix B. Search Strategies by Database......58
Appendix C. EHR Vendor Survey......69
Appendix D. EHR Vendor Interview Guide......72
Appendix E. Excluded Articles......73
Appendix F. Scoping Review Study Characteristics......95
Appendix G. Scoping Review Integration Characteristics......101

Executive Summary

Background/Purpose

The U.S. healthcare system is in a transitional period. Data traditionally collected in a clinic or hospital setting is now able to be collected in everyday environments of patients and is known as patient-generated health data (PGHD). Ambulatory care practices with access to PGHD in their electronic health records (EHRs) may be able to improve patient outcomes, care coordination, quality, and cost-effectiveness.

Opportunity and need for PGHD became apparent in 2020 when the novel coronavirus pandemic abruptly reduced the number of primary and specialty care visits occurring face-to-face, replacing them with telehealth—such as eVisits and telephone calls. Yet identifying which data are needed and supporting patients and clinicians through data capture and transfer into EHRs is highly complex. **Effective use of PGHD in clinics poses many challenges, including clinician and patient burden, poor usability, workflow integration challenges,[1] and the potential to exacerbate health inequities.** The Agency for Healthcare Research and Quality (AHRQ) commissioned an environmental scan that would serve to inform the development of a practical guide that ambulatory care settings can use as they approach the use of PGHD for patient care.

Methods

We sought input from a technical expert panel (TEP) of patients, clinicians, researchers, and EHR experts experienced with integrating PGHD and sharing PGHD with clinicians. The TEP shared their experiences on how PGHD was currently being used and gave feedback on the methods and data collection plans.

This environmental scan addresses knowledge and evidence gaps pertaining to use of PGHD through the following approaches: 1) a *scoping review* that examined the evidence of integrating PGHD into EHRs that expanded on one conducted by Tiase et al. and updated[2,3] through October 2020; 2) a *review of reports* produced by think tanks, government agencies, professional associations, and vendors; and 3) *conversations and surveys* collected from major ambulatory care EHR vendors that serve the majority of the U.S. market to collect information on how their clients are integrating PGHD into EHRs.

Findings

Scoping Review: Our formal scoping review (N=36) provides evidence and examples from peer-reviewed literature on the integration of PGHD into EHRs across a variety of care delivery models in ambulatory care settings (Table 1). Types of PGHD included biometric data, questionnaires/surveys, and health history. Diabetes was the most common patient condition (27.7%). Apple HealthKit was the most common developer platform used (25%). Themes emerged concerning authentication, resource requirements, patient technical support and training, data delivery to the EHR, data management, and preferences for review.

Guides & Resources: Our search of guides and resources presents documents in Table 4 that include a variety of white papers, guides, and resources from professional organizations (e.g., American Medical Association, American Medical Informatics Association), and government agencies (e.g., FDA, ONC), among others. Topics in these documents cover a variety of aspects important to the selection and integration of PGHD in ambulatory care settings. Legislative patchwork at the Federal level governing data privacy, standardization, reimbursement, and regulation is complex and evolving.

EHR Vendors: The growing evidence for PGHD-EHR integration is reflected in the EHR vendor feedback (Tables 3 and 4), which describes a developing landscape in which they partner with institutions to leverage PGHD to improve health outcomes and improve care coordination. iOS HealthKit is commonly used due to its maturity, which provides data and security standardization. Few health systems and EHR vendors directly integrate with Google's Android platform. The use of interoperability standards such as Health Level Seven's (HL7) Fast Healthcare Interoperability Resources (FHIR) is growing. To create value from PGHD, however, requires investment, commitment, and an understanding of many variables that influence the success and challenges of PGHD integration to improve patient outcomes, care coordination, quality, and cost-effectiveness.

Conclusion/Recommendations

We present a thematic summary of recommendations from the scoping review, reports, policies, and data collection from the EHR vendors (Table 7). These recommendations are envisioned to inform the development of a practical guide for ambulatory care providers as they approach the integration of PGHD.

The recommendations are as follows:

1. Develop a strategy or blueprint.
2. Identify champions and early adopters.
3. Tie PGHD to a care delivery model.
4. Design the workflow.
5. Use a patient-focused approach with a health equity lens.
6. Leverage a robust technology architecture.
7. Create data governance.
8. Create device governance.
9. Provide guidance and education to stakeholders.
10. Implement and adapt through iteration.
11. Evaluate against metrics and goals.
12. Plan for maintenance and scaling.
13. Provide technical support.

Chapter 1. Background, Purpose

Patient-generated health data (PGHD) are "health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern."[4] Enthusiasm for use of remote monitoring devices to collect PGHD is high and increasing among researchers, clinics, and health systems. Many mobile health technologies tether to smartphones, Wi-Fi, or have cellular-embedded chips, which have proliferated across socioeconomic groups in the United States.[5] PGHD can be collected in near real-time from patients in their daily environments. The Food and Drug Administration (FDA) policies[6] allow manufacturers of certain FDA-cleared noninvasive, vital-sign-measuring devices that measure biometrics to expand their use so healthcare providers can use devices to monitor patients remotely.

The potential for PGHD to impact health is significant. By providing insights into the day-to-day health of an individual, patients and clinicians can employ better strategies to prevent and manage acute and chronic conditions, and clinicians and scientists can use these data to generate and apply analytical techniques to improve risk prediction and diagnoses.[7] The benefits of PGHD can reach across care facilities and diverse geographic locations through web-based interoperable data exchange to deliver more precise treatment and self-management assistance to broad populations.

While these technologies are promising, the ability for ambulatory care practices to successfully collect these data in collaboration with patients, transfer data to their EHRs, and use them effectively in clinic settings poses many challenges. The Office of the National Coordinator for Health Information Technology (ONC) outlines multiple technical challenges related to accuracy of measurements, data provenance, interoperability, implementation, and privacy and security concerns in the data lifecycle (i.e., collection, transmission, storage, and analysis).[4] In addition, selecting valid devices from an increasing number of options, integration into new care delivery models, costs for patients, equitable access to technology, and inadequate information technology (IT) literacy are among the many challenges facing adoption of PGHD nationwide.

Integration of PGHD into Ambulatory Care Electronic Health Records. As healthcare moves beyond EHR implementation, the integration of PGHD from connected devices, including mobile health technologies, is gaining speed. Companies like Apple Inc. have enabled the ability for patients to aggregate their health records from multiple sources on an iPhone and integrate data via authentication into health system patient portals such as Epic's MyChart. It is also possible to integrate third-party data, such as patient-generated blood glucose levels, into the EHR via Apple HealthKit.[8] This is possible with many major EHR vendors. This capability is quickly expanding to Android platforms with Google Fit and through data aggregation companies such as Validic and Xealth.[9,10]

Ambulatory care practices with access to PGHD in their EHRs may be able to more efficiently and accurately perform diagnoses, manage chronic conditions, reduce repetitious lab testing, promote greater patient-centered care, and even intervene early to avoid acute episodes or prevent hospitalizations. Yet identifying which data are needed and supporting patients through data capture and transfer into EHRs is highly complex.

Standardized interoperable data interfaces are quickly becoming important tools in the integration of PGHD into EHRs. These include standards such as Substitutable Medical Applications and Reusable Technologies (SMART) and FHIR.[11] With the rollout of new ONC interoperability rules requiring healthcare providers who receive Centers for Medicare & Medicaid Services (CMS) payments to use FHIR-compatible apps for patient data, adoption will likely accelerate.[12]

Nascent Body of Evidence on PGHD Use. Policymakers, researchers, IT experts, patients, and providers have been building a body of evidence to (1) identify patient cohorts who can best benefit from PGHD capture, (2) accelerate adoption of IT solutions to support patient transfer of data, and (3) optimize data review by mining large quantities of PGHD to identify patterns and red flags for clinical workflows and care planning. Recent systematic reviews[2,13] advance knowledge about the need for data quality, interoperability, data security, and easy-to-understand clinical and patient self-management insights.

Nevertheless, our collective body of knowledge about PGHD remains inadequate, thus complicating efforts by ambulatory care practices to systematically and efficiently approach these opportunities.

The opportunity and need for PGHD became apparent in 2020 when the novel coronavirus pandemic abruptly reduced the number of primary and specialty care visits occurring face-to-face, replacing them with eVisits and telephone calls.[14] While virtual care and telehealth have the capability to facilitate patient access and increase efficiency of healthcare resources, virtual appointments make it difficult to collect patient-level data essential for diagnosis and chronic disease monitoring. Providers must now rely on patients to collect their own vitals and other health data, which was previously collected in clinic. Virtual care must be implemented strategically to be equitable across diverse populations and clinical conditions so as to not further exacerbate existing health inequities.[15] There is an urgent need to support ambulatory care practices in this complex process through the broad capture and synthesis of PGHD evidence and the translation of that evidence into a practical guide.

Purpose. The Agency for Healthcare Research and Quality (AHRQ) commissioned an environmental scan that would serve to inform the development of a practical guide that ambulatory care settings can use as they approach the use of PGHD for patient care. The study team engaged a technical expert panel (TEP) of patients, clinicians, researchers, and EHR experts experienced at integrating PGHD into the EHR to give input to the environmental scan methods. This input confirmed search terms, data abstraction forms, EHR vendor survey and interview questions, and input on recommendations contained in this report. This environmental scan addresses knowledge and evidence gaps pertaining to use of PGHD in ambulatory care settings through the following approaches: 1) an update to a scoping review by Tiase et al.[3] that examined the evidence of integrating PGHD into EHRs; 2) a review of reports produced by think tanks, government agencies, professional associations, and vendors; and 3) conversations and information collected from major ambulatory EHR vendors in the United States.

Chapter 2. Methods and Approach

Scoping Review

Literature Search. The scoping review expanded one conducted by Tiase et al. by updating the search dates and keywords.[2,3] Databases searched from August 2019 to October 2020 included Medline (Ovid), Scopus (scopus.org), Embase (embase.com), CINAHL Complete (EBSCOhost), Web of Science Core Collection (Clarivate Analytics), Academic Search Ultimate (EBSCOhost), Dissertations & Theses Global (ProQuest), IEEE Xplore (IEEE.org), and INSPEC (Elsevier.com). No filters, such as language or study type, were applied. The final search strategies are presented in Appendix A (Tiase orginial search[2]) and Appendix B (updated search). To search unpublished studies and grey literature, we used the Google search engine, limited to the first 50 results, using terms including patient-generated health data, user- generated health data, mobile health, self-tracking, integration, and electronic medical record. Two reviewers (GP, SB) searched Google simultaneously at different locations to account for differences in results.

Study Selection. Search results were imported into Covidence (Veritas Health Innovation, n.d.) systematic-review software for screening. Researchers (MB, GP, JW, VT) conducted title, abstract, and full-text screening. Each researcher tested the screening criteria on a sample of titles and abstracts to ensure that the criteria were robust enough to capture eligible articles. If an article abstract was not accompanied by the full text of the article, we contacted the authors by email. If there was no response, we excluded the abstract. In the second level of screening, the researchers independently assessed the full text to determine eligibility. We held regular meetings to achieve consensus and conflicts were resolved with input from two other researchers (RS, RD). We recorded the reason for full-text exclusion in Covidence.

Data Abstraction and Analysis. Using the themes and details from the Tiase review,[2,3] we created a form in Qualtrics for the data abstraction of articles included from the full-text review. One researcher (MB, GP, or JW) completed the first abstraction, and the results were over-read by a second researcher (VT). Any conflicts were resolved with input from two other researchers (RS, RD). The articles were categorized in the same themes, and we used frequency analyses to describe the data.

EHR Vendor Survey and Interview

Survey and Interview Guide Development and Approach. We contacted ambulatory EHR vendors (N=9) that serve 95% of the U.S. market to collect information on how their clients are integrating PGHD into EHRs. We assessed what PGHD their clients are using or plan to integrate into their EHR, including PGHD type (e.g., biometric, patient activity, questionnaires, health history), PGHD transfer (e.g., active, passive), and technical approaches (e.g., HL7, APIs, Bluetooth). We asked about interoperability standards (e.g., SMART, FHIR, HL7v2, web services, extensible markup language [XML], and consolidated-clinical document architecture [C-CDA]); whether design schemas such as Open mHealth and standardized medical coding terms are leveraged (e.g., SNOMED, LOINC, RxNORM); and what developer platforms (e.g., Apple HealthKit, Google Fit) and which tools, products, and 3rd-party companies (e.g., Fitbit, Garmin) integrate data into their EHRs.

To collect this information, we invited vendor representatives (from November 2020 to February 2021) to complete an online survey, and then participate in a followup interview. Vendor representatives were familiar with the processes involved and the state of PGHD integration into their company's EHR. The survey and interview guide were developed by our team with feedback and expert opinion from the TEP. Through iteration we refined the question set with approval from AHRQ (See Appendices C and D). We contacted vendors at least twice in attempt to have them complete an online survey in Qualtrics. Data were analyzed using descriptive statistics.

Following completion of the survey, we invited vendors to a 45-minute video interview. Vendors were asked 10 questions exploring factors contributing to the successes and challenges of integrating PGHD into EHRs. Interviewers took notes during the interview and asked permission to record interviews. Data regarding the successes, challenges, and resources of PGHD were analyzed using content analysis to identify recurring themes in the interviews.[16] We described other feedback from vendors as a summary narrative.

Reports, Guides, and Policy

Review of Reports and Guides. We searched reports produced by think tanks, professional organizations, government agency (e.g., AHRQ, ASPE, ONC, FDA, FTC), EHR vendors, and healthcare facilities. We used Google as the search tool using terms, "patient generated health data, PGHD, digital health, electronic health record, white paper, report, guide." Relevant reports and guides were cataloged. These documents were reviewed and key findings were described.

Policy, Regulation, and Reimbursement. Similarly, we searched reports by think tanks, professional organizations, and government agencies (e.g., Congressional Research Service; HHS, including MLN Matters; the federal register; AHRQ, ASPE, ONC, FDA, FTC). Google was the primary search tool using terms that included, "security, privacy, law, rule, patient generated health data, PGHD, digital health, electronic health record, white paper, report, guide." Key findings were described.

Technical Expert Panel (TEP)

Expert Input. The TEP provided real-world experience with PGHD by offering guidance on inclusion criteria, identifying articles of materials that may have been missed, and helping us refine data abstraction elements. The TEP provided feedback on survey and interview questions posed to EHR vendors. The TEP's diverse background provides the perspectives of patients, clinicians, researchers, and health IT experts who are experienced at integrating PGHD into the EHR. After TEP revision and approval of the inclusion criteria and data abstraction elements, we screened relevant articles and other grey literature.

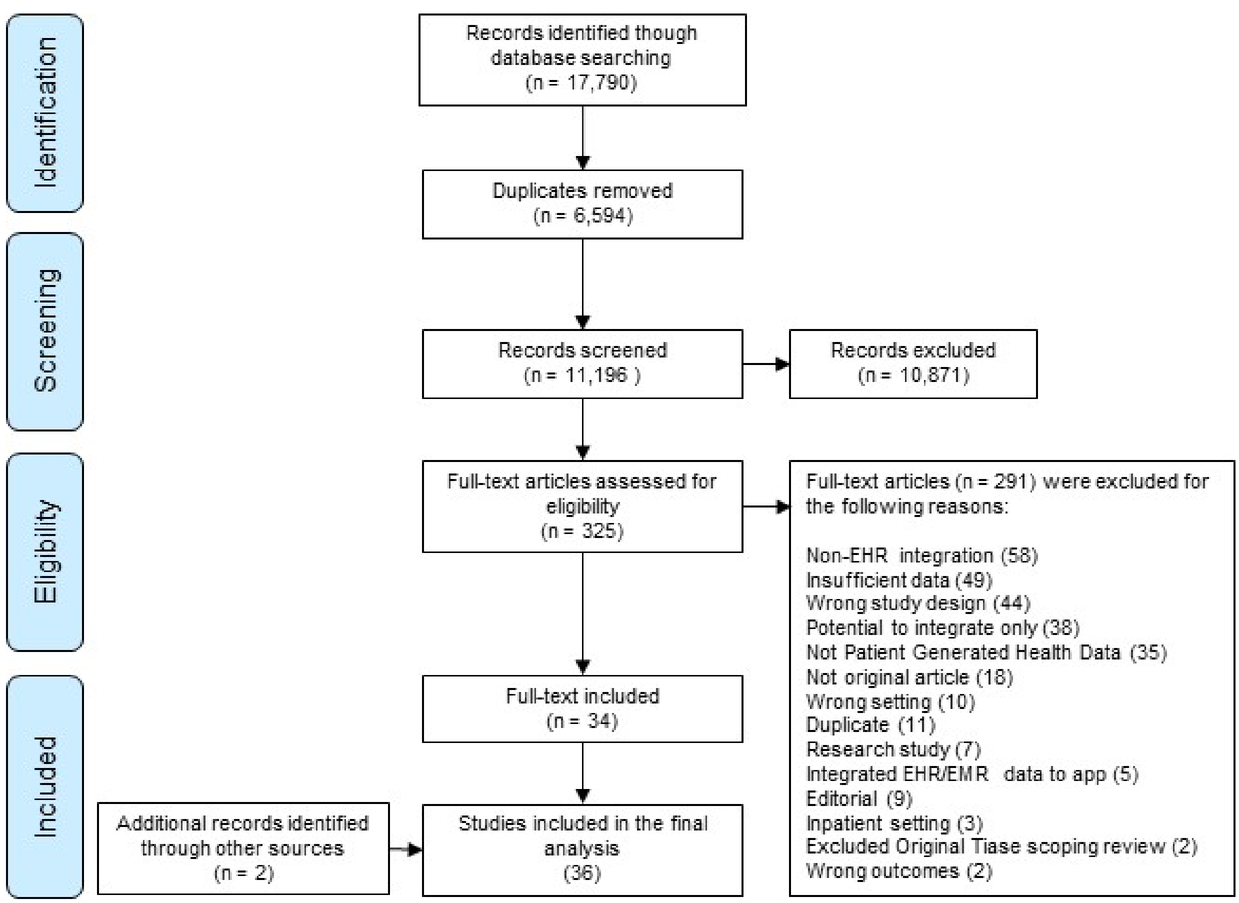
The TEP provided feedback to the environmental scan and assisted with curated recommendations and information learned so that it could be used in the development of the practical guide.

Chapter 3. Results

Scoping Review

Search Results. The search identified 3,086 citations, of which 1,353 were duplicates, thus leaving 1,733 new citations for title and abstract screening since the Tiase review. Figure 1 shows the combined number of studies from the previous and updated literature searches. Together, the search parameters identified 17,790 studies. Of these, 6,594 duplicates were removed, 10,871 were excluded after title and abstract screening, and 325 underwent full-text screening. In total, 36 articles were included in our review—16 from the original Tiase review and 20 from the updated search (Figure 1). All selected articles were published between 2013 and 2020. The majority were published in 2020 (n=15; 38.8%) and 2019 (n=10; 27.7%). Most of the articles were published in North America (n=28; 77.8%), followed by Europe (n=4; 11.1%), Asia (n=2; 5.6%), and Australia (n=2; 5.6%). The majority of studies were either in the non-academic ambulatory care setting (n=17; 47.2%) or academic ambulatory care setting (n=15; 41.6%); the remaining studies were in cancer centers (n=4; 11.1%) (see Figure 1).

Figure 1. Flow diagram for study selection process



Study designs varied with the largest design being observational (n=8; 22.2%), followed by experimental (n=6; 16.6%), mixed-methods (n=6; 16.6%), qualitative (n=4; 11.1%), and other (n=7; 19.4%). As shown below in Table 1, included studies report on the use of PGHD tools with patients living with diabetes (including type 1, type 2, and gestational, n=10; 27.7%), cancer (n=8; 22.2%), multiple conditions (n=6; 16.6%), and other (n=12; 33.3%) conditions (e.g., inflammatory bowel disease).

PGHD Characteristics and Integration. Selected studies reported on integrated biometric data such as heart rate or blood glucose, patient-reported outcome (PRO) measures/surveys, or health history data. Half of the studies (n=18; 50.0%) reported on integrated biometric data alone, and the remaining studies were split between questionnaires (n=15; 41.6%), biometric data and questionnaires (n=2; 5.5%), and health history (n=1; 2.7%). We evaluated the specific devices and questionnaires used for data capture. Within the biometric data studies, multiple groups captured more than one biometric data element.

Biometric data included blood pressure (n= 8; 22.2%), blood glucose (n=7; 19.4%), physical activity (n=5; 13.9%), heart rate (n=3; 8.3%), pulse oximetry (n=3; 8.3%), weight (n=3; 8.3%), sleep (n=2; 5.6%), temperature (n=1; 2.8%), digital EKGs (n=1; 2.8%), FEV-1 measures (n=1; 2.8%), and captured images of skin (n=1; 2.8%). Devices used for capture of biometric data were all commercially available and included the Fitbit, Apple watch, Accu-check Aviva Connect, DexcomG4 Platinum CGM, Omron HEM- 790 ITBP, and the A&D UC-352BLE digital weight scale. Within studies that reported utilizing questionnaires, data captured focused on disease severity or symptoms (n=14; 38.9%), quality of life or function (n=6; 16.7%), medication utilization (n=5; 13.9%), or emergency room visits (n=1; 2.8%).

Finally, within studies utilizing PROs, only two studies (5.6%) utilized adaptive PROs.

The majority of selected studies reported on data integration in the Epic EHR system (n=23; 63.8%), followed by MOSAIQ (n=2; 5.5%), Allscripts (n=1; 2.7%), GE Centricity (n=1; 2.7%), and Bestcare 2.0 (n=1; 2.7%). Some reports did not report the linked EHR system (n=8; 22.2%). A large subset of studies did not provide information on the developer platform utilized for their PGHD (n=12; 33.3%). Some used commercially available platforms including Apple Health kit (n=9; 25.0%), Epic (n=4; 11.1%), Validic (n=2; 5.6%), and Microsoft Healthvault (n=1; 2.8%). The majority of included articles (n=25; 69.4%) did not report information on the approach to data transfer or integration. The remaining reported utilizing Bluetooth for data transfer (n=2, 5.5%), and HL7 (n=6; 16.7%) or APIs (n=3; 8.3%) for data integration into the EHR. In many instances (n=12; 33.3%), PGHD data were manually entered by the patient into the EHR's native patient portal, which reduced the complexity of PGHD-EHR integration.

Thematic Analysis

Consistent with the scoping review conducted by Tiase et al.,[3] we categorized content integration into three primary categories: data capture, data transfer, and data review.

Data Capture. We broadly evaluated studies for their reports in relation to data authentication, technical support, training resources, and device expenses. Data authentication was unclear or not reported in most of the studies (n=19; 55.6%). In the remainder, authentication was either conducted in the patient portal (n=14; 38.9%), via an API wrapper linked to the patient portal (n=1; 2.8%), by email (n=1; 2.8%), or via text messaging (n=1; 2.8%). To ensure purity of captured data and improve the patient experience, multiple studies (n=13; 36.1%) reported either utilizing in-person (n=9; 25.0%), manualized (n=1; 2.8%), or combined (n=1; 2.8%) training for patients. One study (2.8%) reported training patients but did not report the method used, and another study (n=1; 2.8%) utilized telehealth training for patients. Finally, while many studies utilized project-specific staff to train patients on device usage, two studies (5.6%) required that clinicians conduct the patient training at the clinic encounter.

Technical support resources were offered to patients by some studies (n=6; 16.7%). Patient responsibility for the device expense was not reported in many instances (n=16; 44.4%). Of those who did report device expense (n=20; 55.6%), the majority of them (n=18; 50%) reported making devices freely available to patients, and two studies stated that the patient device expense was less than $50 (n=1; 2.8) or between $50-$250 (n=1; 2.8%).

Data Transfer. To examine data transfer, we specifically addressed four elements: EHR delivery, data collection and transfer frequency, connectivity, and development time. Regarding delivery, studies were evaluated for whether data transfer was passive (n=14; 38.9%), active (n=13; 36.1%), or both (n=5; 13.9%). Early studies reported that mode of data transfer did extend to not just the patient but, in some instances, provider involvement in ensuring appropriate data transfer (n=6; 16.7%). One group reported that providers were required to file data to the appropriate patient record.[17] Provider arbitration of data transfer was not required in more recent studies. Frequency of data collection and transfer varied by study and the type of PGHD collected. Data collection varied across groups. For those utilizing biometric data, collection ranged from every 1-10 seconds for heart rate measures to three times a week for a group collecting blood glucose and activity. For those utilizing PROs or patient histories, some studies only required data input prior to clinical appointments (n=3; 8.3%), via the provider's formal order for collection (n=1; 2.8%), or allowed for patient autonomy over frequency of data collection (n= 2; 5.6%). The remaining studies had set time frames ranging from daily to monthly (n=9; 25.0%). In some studies, once the PGHD was collected, it was then transferred to the EHR in real time (n=12; 36.1%). One study required that patients review and approve their collected health data prior to upload into the EHR.

Connectivity was an issue reported in some studies (n=6; 16.7%), which were secondary to software updates, operating system compatibility, and/or internet browser compatibility. In some studies, device compatibility problems were reported. One study reported having challenges related to a device recall.[18] Few studies reported on the development time of their product (n=9; 25.0%), which ranged from less than 1 year (n=7; 19.4%) or over 1 year (n=2; 5.6%]. One study reported developing infrastructure within 2 days,[19] which occurred during the global COVID-19 pandemic and was facilitated by significant organizational buy-in, stakeholder motivation, and financial/human resource availability.

Data Review. We evaluated articles for information on provider training and technical support, provider notifications, and data display options. Few studies (n=4; 11.1%) reported providing clinician training. Of these, three (8.3%) conducted in-person training with providers, and one (2.8%) utilized manualized training. A minority reported having technical support available for providers (n=4; 11.1%).

Studies did utilize alert systems to produce a notification when captured data exceeded certain thresholds. The approach to notifications included: 1) utilizing a triaging coordinator or dedicated staff (n=3; 8.3%) who alerted providers after data review and contact with patients when appropriate; and 2) directly notifying providers in the EHR (n=9; 25.0%), either via EHR in-basket activity (n=3; 8.3%), or by email (n=2; 5.6%). Where alert thresholds were set, four studies (11.1%) reported that alert thresholds were set by providers. Three studies reported that notifications were not used (8.3%). There was limited information on how the PGHD were displayed within the EHR. Data were displayed either in dashboards (8; 22.2%), directly in the patient record (9; 25.0%), in flowsheets (n=2; 5.4%), in synopsis views (n=2; 5.4%), or through an integrated web app (n=1; 2.7%).

Pragmatics of PGHD. Many studies (n=15; 41.7%) reported outcome measures for patients and providers regarding PGHD utilization. In studies where patients were required to manually input data into the EHR, completion rates ranged from 10% to 100%. The completion rate varied by data upload frequency. One study reported that surveys requiring more frequent (weekly) uploads had higher completion rates (61%) compared to those requiring less frequent (monthly) uploads (54%).[20] Although patient survey completions varied, patient satisfaction was generally high. Six studies reported satisfaction metrics and perception of ease of use ranging from 72% to 94%; patients reported that PRO use increased reassurance around care, and in one study 70% of patients reported that using the system aided their self-management.[21]

Table 1. Summary of study characteristics and thematic organization (N=36)

	Characteristics	Number (%)
Year of Publication	2013	2 (5.5%)
	2014	1 (2.7%)
	2015	1 (2.7%)
	2016	2 (5.5%)
	2017	2 (5.5%)
	2018	4 (11.1%)
	2019	10 (27.7%)
	2020	14 (38.8%)
Geographic Region	North America	27 (75.0 %)
	United Kingdom	2 (5.5 %)
	Australia	2 (5.5 %)
	Korea	2 (5.5 %)
	Belgium	1 (2.7 %)
	Canada	1 (2.7 %)
	Scotland	1 (2.7 %)
Evaluation Design	Observational	8 (22.2%)
	Descriptive	3 (13.8%)
	Experimental	6 (16.6%)
	Qualitative	4 (11.1%)
	Mixed Methods	6 (16.6%)
	System Description	3 (13.8%)
	Pilot Study	1 (2.7%)
Study Setting	Outpatient or Clinic	17 (47.2%)
	Cancer Center	4 (11.1%)
	Academic Medical Center	15 (41.6%)
Target Population	Diabetes	10 (27.7%)
	Cancer	8 (22.2%)
	Hypertension	2 (5.5%)
	Orthopedic Surgery	2 (5.5%)
	Multiple Conditions	6 (16.6%)
	Asthma	2 (5.5%)
	Arrhythmia	1 (2.7%)
	COVID-19	2 (5.5%)
	Inflammatory Bowel Disease	1 (2.7%)
	Hepatic Ascites	1 (2.7%)
	Prostate-Specific Antigen Screening	1 (2.7%)
Patient Generated Health Data (PGHD) Type	Biometric and Patient Activity	18 (50.0%)
	Questionnaires and Surveys	15 (41.6%)
	Biometric and Surveys	2 (5.5%)
	Health History	1 (2.7%)

	Characteristics	Number (%)
Electronic Health Record	Epic	23 (63.8%)
	Unidentified/Not Reported	8 (22.2%)
	MOSAIQ	2 (5.5%)
	Allscripts	1 (2.7%)
Electronic Health Record	GE Centricity	1 (2.7%)
	BESTCare 2.0	1 (2.7%)
Patient Generated Health Data (PGHD) Transfer	Active	13 (36.1%
	Passive	14 (38.8%
	Both	5 (13.8%)
	Not reported	4 (11.1%)
Technical Approach	Health Level 7 (HL7)	5 (13.8%)
	Application Programming Interface (API)	3 (8.3%)
	Bluetooth	2 (5.5%)
	QStore	1 (2.7%)
	Not Applicable	1 (2.7%)
	Not Reported	24 (66.6%)
Developer Platform	Apple HealthKit	9 (25.0%)
	Northwestern Medicine Patient-Reported Outcomes	2 (5.5%)
	Epic Toolkit	1 (2.7%)
	Microsoft HealthVault	1 (2.7%)
	Validic	2 (5.5%)
	Technology Enabled Asthma Management System	1 (2.7%)
	Epic MyChart	2 (5.5%)
	PRO Tool in Epic	1 (2.7%)
	myNEXUS Health	1 (2.7%)
	PGHD Connect	1 (2.7%)
	QTool by X-lab	1 (2.7%)
	Mobile App via HealthConnect	1 (2.7%)
	Home Monitoring App	1 (2.7%)
	Not Reported	12 (33.3%)

Table 2. Summary of biometric data and hardware utilized to measure

Measured Biometric Data	Hardware
Sleep	iPhone, iPod Touch, Fitbit
Oximetry	Fitbit
Weight	A & D UC352BLE digital scale
Heart Rate	iPhone, iPod Touch, Apple Watch, Fitbit
Blood Glucose	Dexcom G4 Platinum CGM, Accu-Chek Aviva Connect
Blood Pressure	Omron HEM-790IT BP Monitor Omron HEM-670IT BP Monitor A & D Medical, Mode UA-767 BT-Ci
Activity	iPhone, iPod Touch, Apple Watch, Fitbit

Table 3. Summary of content integration

Category	Theme	Number of Articles
Data Capture	Authentication	16
	Patient Technical Support	6
	Patient Training Resources	13
	Device Expenses	20
Data Transfer	EHR Delivery	32
	Development Time	9
	Connectivity	6
Data Review	Notifications	15
	Display Options	21
	Provider Technical Support	4
	Provider Training Resources	4

Studies also evaluated provider use of PGHD. Eight studies (22.2%) provided content on provider PRO usage. The lowest provider usage of PRO review tools was reported to be 6.4%.[22] Interestingly, even in instances where alerts were generated, provider usage was occasionally low with one study reporting alert reviews were conducted by 44% of clinicians.[23] However, one study utilizing patient-generated weight data to evaluate ascites volume in cirrhotic patients found that clinician alert response rates from clinicians were as high as 84%.[24] Finally, of those studies that reported on health-specific outcomes (n=7; 19.4%), five studies (13.9%) found improvement while two found the use of PGHD to have no impact on outcomes. One of these studies had used PGHD to improve patient utilization of aromatase inhibitors.[25]

Exemplars from the Literature

We identified resources from the literature that may serve as exemplars in the integration of PGHD into ambulatory care settings. We present on a number of frameworks, case studies, and more.

Perspectives, frameworks, barriers, and facilitators. Lavallee et al.[26] report stakeholder perspectives on a broad range of PGHD types (including biometric and PRO data) and describe six themes and a number of values and barriers. These themes include: 1) PGHD tracking supports many healthcare goals and behaviors, 2) people are intentional about timing and types of data they share with their providers, 3) the value of PGHD increases with alignment to measurement-based care, 4) data provide a common framework that facilitates patient engagement, 5) the promise of PGHD is tempered by lack of standards, and 6) unintended consequences of PGHD need further exploration. They describe value as providing access to care, accountability, awareness of health, goal tracking, improved communication, improved recall, increased motivation, patient engagement, and quantifying health. However, barriers include deficiencies in accessibility, accountability, actionality, buy-in, data integration, evidence for use, incentive for use, and standards, as well as burden of tracking, feasibility, limited resources, suitability of use, and unknown accuracy of data.[26]

Abdolkhani et al.[27] described data management and quality challenges with using PGHD for remote monitoring. Challenges included digital health literacy, wearable accuracy, data interpretation, and lack of PGHD integration with the EHR. They stressed the importance of developing quality guidelines with all relevant stakeholders that must include patients.[27] Other important articles include a review on converging and diverging needs between patients and providers who are collecting and using PGHD.[13] Austin et al.[28] evaluated stakeholder experiences of PGHD integration into clinical care at the University of Washington Medicine System. The group found that stakeholders utilized PGHD to improve symptom monitoring, personalize interventions, monitor care plans, assess clinical outcomes, promote self-management and behavior change support, prevent illness, and improve care delivery and quality assurance. The study team reported that 71 different PGHD types were being used at their institution, including physical activity, mood, and sleep data. Over half of the PGHD reported were used to track daily activities or symptoms. They further described a number of barriers to institution-wide scaling, with the two most significant being PGHD integration into clinical records and organizational infrastructure or policies to support PGHD.[28] Similarly, Adler-Milstein and Nong[29] interviewed leaders from health systems, EHR and PGHD solutions, and patients. They identified three approaches to the use of PGHD, including health history, validated questionnaires and surveys, and biometric and health activity. They noted patient concerns about data security and value of reporting PGHD. Health systems reported reimbursement, data quality, and clinical usefulness challenges. Uncertainty around value for stakeholders, patients, and providers was the primary inhibitor.[29]

A meta-synthesis of five studies from Project HealthDesign that developed, tested, and implemented technologies for collecting observations of daily living is reported by Cohen et al.[30] They describe a model with six factors that motivate patients to collect these data. These factors include: 1) usability, 2) illness experience, 3) relevance of observations of daily living, 4) information technology infrastructure, 5) degree of burden, and 6) emotional activation. These factors may act as facilitators and barriers that influence data collection, health-related awareness, and behavior change.[30] Their team also reported on barriers and facilitators to the use of PGHD among five additional studies from Project HealthDesign Round 2.[31] Healthcare professionals interviewed identified three benefits and three barriers. The benefits reported were that PGHD provides deeper insight into a patient's condition, more accurate patient information of clinical relevance, and insight into a patient's health between clinic visits. Barriers to use of PGHD in clinics include: developing practice workflows and protocols; data storage, accessibility at the point of care, and privacy concerns; and ease of using PGHD.[31]

Case studies. Bachmann et al.[32] present an implementation strategy for systematic measurement of PGHD. They describe a three-phase approach that begins with an exploration phase focused on engaging leadership and conducting an inventory of current efforts to collect PGHD. The second phase is preparatory, with steps including pilot implementation site selection, and development of needs assessment and timeline. The third phase adapts technology platforms and the EHR to implement PGHD into clinical sites. They note the complexity involved necessitates change management at the enterprise level.[32] An example of implementing PROs in oncology rehabilitation by Winter et al.[33] describes a similar yet four-step process that entails a fourth maintenance and evolution phase and emphasizes the importance of technical support and training across phases. Stover et al.[34] described the importance of stakeholder engagement to overcome barriers to implementing PROs in oncology care delivery. Clinician and patient input were critical to identifying symptoms and PRO measures for implementation success.

A case study by Shaw et al.[35] describes a method guided by a telehealth model to evaluate the selection of mobile health technologies for EHR integration. Their case study stresses the importance of a multidisciplinary assessment, including elements of health equity and socioeconomics. Pevnick et al.[36] describe a quality improvement project where patients allowed PGHD from wearable heart monitors to be uploaded into the EHR. They describe a framework to address these PGHD, including data visualization and protocols identifying concerning heart rates to trigger a cardiologist review. A recent AHRQ-funded study assessed the feasibility of using commercial health technologies to collect and report PGHD and PROs from diverse, disadvantaged patients in an urban safety net healthcare system. They found patients preferred providers to recommend technology to rather than self-selection. Providers preferred to receive a summary of PGHD and PRO data closer to clinic visits versus a stream of data over time.[37]

FHIR. There were no studies from the scoping review that met our strict inclusion criteria that discussed the use of FHIR to support the integration of PGHD. Amongst our excluded studies, two studies provide examples from inpatient settings that could be transferred to remote monitoring outpatient and home settings. Ploner and Prokosch[38] present a systems architecture and FHIR-based data model that includes security measures and application flow from patients' smartphones and a public cloud infrastructure at the University Hospital of Elrangen, Germany. A relevant approach by a team in South Korea describes a FHIR-based mobile alert system using 12-lead electrocardiograms.[39]

Quality metrics and cost-effectiveness. PROs may be useful for reporting quality metrics. One study demonstrates using electronic PROs as an effective way to screen for pain and depression, for symptom monitoring and physician-patient communication, and for providing an audit trail for Quality Oncology Practice Initiative (QOPI) metric reporting.[40]

Guides, Reports, and Resources on the Integration of PGHD into EHRs

Table 4 presents 14 documents that include a variety of white papers, guides, and resources from the FDA, AHRQ, ONC, American Medical Association (AMA), American Medical Informatics Association (AMIA), and the Patient-Centered Outcomes Research Institute (PCORI), among others. Topics covered include a variety of aspects important to the selection, integration, and use of PGHD for clinical care in ambulatory care settings. These include: 1) the use of PGHD in telehealth care delivery models; 2) strategic planning on creating a team, targeting patient populations, and creating value from PGHD; 3) selecting, integrating, and visualizing data; 4) frameworks for understanding standards and criteria for interoperability; 5) design principles for diverse patient populations; 6) guidance on which PGHD and associated devices fall under FDA oversight; and 7) social, ethical, and legal considerations.

Table 4. Guides and reports related to PGHD

Document Name	Organization	Date	Key Findings and Elements
Automated-Entry Patient Generated Health Data for Chronic Conditions: The Evidence on Health Outcomes	*Agency for Healthcare Research and Quality (AHRQ)*[41]	2021	• Evidence review of automated-entry PGHD devices and mobile apps for the prevention or treatment of 11 chronic conditions • Characteristics (e.g., interoperability, usability, sustainability, feasibility, fidelity, or integration into EHRs) of consumer automated-entry PGHD technologies. Found a "possible positive effect" of PGHD interventions on health outcomes for coronary artery disease, heart failure, and asthma. Findings were "unclear" regarding PGHD interventions for obesity, diabetes prevention, sleep apnea, stroke, Parkinson's disease, and chronic obstructive pulmonary disease. • Economic evaluations and value for consumers
Telehealth Implementation Playbook	*American Medical Association (AMA)*[42]	2020	• Description of telehealth, benefits, barriers, and commons uses • Timeline of steps: Identifying a need, forming the team, defining success, vendor evaluation, making the case, contracting, designing workflow, preparing care teams, patient partnering, implementation, evaluation, scaling
Continua Design Guidelines	*Personal Connected Health Alliance*[43]	2019	• Framework of underlying standards and criteria required to ensure the interoperability of components used for applications monitoring personal health and wellness • Standards and implementation guidelines across a series of areas: system overview, personal health devices interface, services interface, observation upload capability, questionnaire capability, exchange capability, authenticated persistent session capability, healthcare information system interface
Usability and Design Features for the Aging Population in Connected Health	*Personal Connected Health Alliance*[44]	2019	• Principles of Universal design for aging and health technology • Design principles: equitable use, flexibility in use, perceptible information, tolerance for error, low physical effort, size and space for approach and use
Policy for Device Software Functions and Mobile Medical Applications	*U.S. Food and Drug Administration (FDA)*[45]	2019	• Definitions on a mobile platform, mobile app, mobile medical app, regulated medical device, mobile medical app manufacturer • Regulatory approach for device software functions including when enforcement discretion is exercised • Examples of what is not a medical device, those for which FDA intends to exercise enforcement discretion, and software/mobile medical apps that fall under FDA regulatory oversight
The Futures of Health: Social, Ethical, and Legal Challenges	*Humboldt Institute for Internet and Society*[46]	2019	• Social and cultural challenges and questions • General legal research perspectives from the EU and beyond • General Data Protection Regulation (GDPR) • International case studies
Determining Real-World Data's Fitness for Use and the Role of Reliability	*Duke-Margolis Center for Health Policy*[47]	2019	• A framework for how to systematically evaluate whether real-world data are fit for use by using verification checks to assess reliability • Concepts to be evaluated in assessments of reliability, including completeness, conformance, and plausibility of real-world data • Considerations for applying the framework to EHR data and PGHD

Document Name	Organization	Date	Key Findings and Elements
Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient- Generated Health Data in Care Delivery and Research through 2024: Practical Guide	The Office of the National Coordinator for Health Information Technology (ONC)[48]	2018	• Strategic planning: defining objectives, business case, securing sponsorship • Defining requirements: gathering requirements, identifying patient-facing technologies • Implementing: training staff, enrolling patients, sustaining engagement, reviewing and acting on PGHD, supporting users • Monitoring and adapting: addressing data-related liability, privacy and security laws, and regulations
Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient- Generated Health Data in Care Delivery and Research through 2024: White Paper	The Office of the National Coordinator for Health Information Technology (ONC)[49]	2018	• Describes key opportunities and challenges and offers enabling actions that can further enhance PGHD capture, use, and sharing for healthcare delivery and research in the United States • Provides enabling actions across stakeholder groups: patients and caregivers, clinicians, researchers, policymakers, developers and standards bodies, and payers and employers • Two demonstration pilots: Validic (Sutter Health) and TapCloud (AMITA Health)
Digital Health Implementation Playbook	American Medical Association (AMA)[50]	2018	• Remote patient monitoring and implementation • Timeline of steps: Identify a need, form the team, define success, vendor evaluation, make the case, contract, design workflow, prepare care teams, patient partnering, implementation, evaluation, scaling
Leveraging Patient-Generated Health Data to Improve Outcomes and Decrease Cost	eHealth Initiative[51]	2018	Overview of PGHD, how it's collected, use in patient care, support to value-based care reimbursement, data visualization and interoperability, privacy and security
Health Industry Cybersecurity Practices: Managing Threats and Protecting Patients	US Department of Health and Human Services (DHHS)[52]	2018	• Managing cybersecurity threats and vulnerabilities • Toolkit to help organizations prioritize they cyber threats and develop action plans
Redefining Our Picture of Health: Towards a Person-Centered Integrated Care, Research, Wellness, and Community Ecosystem	American Medical Informatics Association (AMIA)[53]	2017	• A series of policy recommendations developed across problem statements: data standards, data governance and ethical frameworks, data sources across the home and community, participatory methods and citizen science, outcome measures, trust and transparency frameworks, and supporting diverse people • Recommendations are reorganized and categorized into a policy framework intended to promote a person-centered informatics infrastructure and data ecosystem.
Users' Guide to Integrating Patient-Reported Outcomes in Electronic Health Records	Patient-Centered Outcomes Research Institute (PCORI)[54]	2017	• Strategy for integrating PROs in EHRs, governance, training, and engaging users • Targeting patient populations, measuring outcomes, evaluating PRO candidate measures • Displaying PROs in the EHR • Acting upon PROs, pooling data from multiple EHRs • Ethical and legal issues

EHR Vendor Survey and Interviews

Of the 9 EHR vendors contacted, 6 completed the survey and 5 participated in a 45-minute interview. Vendors interviewed serve approximately 80% of the US ambulatory care market.[55] EHR vendors described factors that contribute to integration of PGHD into EHRs. Table 5 shows results from the survey. Table 6 describes themes that arose around success, challenges, and resources needed.

EHR vendor survey. Of the six vendors who responded, nearly all (n=5, 83%) stated they allow for PGHD to be integrated (ingested). The timeline since integration began ranges between 2–10+ years. The five that allow for PGHD to be ingested are further described. All (n=5, 100%) provide pre-built and custom-built functionality to process and manage PGHD, and PGHD is part of the original contract for some (n=3, 60%) and an add-on for others (n=2, 40%). Nearly all (n=4, 80%) allow for a 'bring your own device' (BYOD) model, and most (n=3, 60%) allow for PGHD to be received out of the patient portal.

Some have functionality to notify providers and patients (n=3, 60%) if PGHD need action or are out of range. Vendors provided further details as comments to these questions. It is an implementation decision to select what type of notifications the client (clinic) may want based on the PGHD. PGHD may appear in a dashboard for clinicians to review to identify patients with high risk in need for outreach. Triggers can automatically send messages to providers or page a nurse pool based on incoming data. Notifications can also be developed that remind patients to complete PROs, submit data, or perform action based on data received.

All (n=5, 100%) stated their EHR has the capability to send patient data from the EHR to mobile health apps. All use iOS HealthKit (n=5, 100%), some use Android's Google Fit (n=2, 40%) and other partner platforms (n=2, 40%) to integrate PGHD. HealthKit is easier for vendors to leverage due to the maturity of the Health App which provides data and security standardization. Three vendors (60%) responded their tool provided these data from mobile health apps in graphical format for clinicians within the EHR. The variety of data that could be ingested varied by the aggregator source. iOS HealthKit allows for a variety of data to be tethered to the Apple Health App. Thus, any data integrated with HealthKit could be pulled in. Similarly, partnering with a data aggregator company like Validic or Raziel Health allows for additional types of data to be pulled into an EHR. Other partner vendors reported included Livongo, TytoCare, IdealLife, Fitbit, Garmin, Omron, Qardio, iHealth, Welch-Allen, and Withings. While it may be technically possible to pull in dozens if not hundreds of data types from remote health monitors and PRO surveys, the need or value to do so must be tied to a care delivery model.

With regard to the transfer of data, all (n=5, 100%) allow for passive transfer while most (n=4, 80%) allow for push, active, and pull. The technical approach by vendors varies with FHIR (n=4, 80%) standard APIs (n=3, 60%), and web services (n=3, 60%). The use of standardized medical coding terminologies (e.g., SNOMED, LOINC) varied across vendors. Leveraging FHIR was recommended and encouraged to create data standards across the industry to facilitate integrating mobile health app data into EHRs. None of the vendors use design schemas such as Open mHealth or IEEE P1752 standards process.

Only one vendor (20%) stated they were able to consume or translate incoming PGHD into another language, which was Spanish. Though it was stated that clients that work with this vendor have the ability to translate data into other languages, it was unclear if anyone has done this yet. Three (60%) provide PGHD resources through their patient portal. These resources may include instructions for connecting devices, collecting and uploading data, and what to do if results are out of normal range. Some vendor systems allow patients to connect to supported devices without practice assistance or tech support (n=3, 60%), and some require a clinic to activate prescribed devices (n=3, 60%).

Table 5. EHR vendor survey responses (N=6)

Question	Answer	Number (%)
Does your EHR allow for PGHD to be ingested? (N=6)	Yes	5 (83)
	No	1 (17)
Do you allow for a bring your own device (BYOD) model? (n=5)	Yes	4 (80)
	No	1 (20)
To process and manage PGHD does your EHR require custom-built or pre-built functionality, or both? (n=5)	Both	5 (100)
Is PGHD inclusion part of the original contract with clients or an add-on? (n=5)	Original contract	3 (60)
	Add-on	2 (40)
Can PGHD be received outside of the patient portal? (n=5)	Yes	3 (60)
	No	2 (40)
Is PGHD accessible by providers/health system to intervene? (n=5)	Yes	4 (80)
	No	1 (20)
Does your EHR have functionality to notify providers regarding PGHD (e.g., exists, needs action, or is out of range)? (n=5)	Yes	3 (60)
	No	2 (40)
Does your EHR have functionality to notify patients regarding PGHD (e.g., exists, needs action, or is out of range)? (n=5)	Yes	3 (60)
	No	2 (40)
Does your EHR have the capability to send patient data from the EHR to mobile health apps? (n=5)	Yes	5 (100)
	No	0 (0)
Does your EHR allow for the push/active or pull/passive transfer of PGHD? (n=5)	Push, active and pull	4 (80)
	Passive	5 (100)
What technical approach to PGHD integration does your EHR support? (n=5)	HL7	4 (80)
	FHIR	4 (80)
	Standardized APIs	3 (60)
	Web services	4 (80)
Does your EHR use design schemas such as Open mHealth? (OmH; IEEE P1752 standards process)? (n=5)	Yes	0 (0)
	Not sure	4 (60)
	No	2 (40)
What platforms does your EHR partner with to integrate PGHD? (n=5)	iOS HealthKit	5 (100)
	Android Google Fit	2 (40)
	Other	3 (66)
Does your EHR have the ability to translate PGHD in different languages? (n=5)	Yes	1 (20)
	Not sure	1 (20)
	No	3 (60)

Question	Answer	Number (%)
Are there readily available resources through your patient portal for patients about PGHD? (n=5)	Yes	3 (60)
	Not sure	1 (20)
	No	1 (20)
Patients have the ability to easily connect to supported devices without practice assistance or tech support (n=5)	Yes	3 (60)
Patients require a clinic to activate prescribed devices (n=5)	Yes	3 (60)

EHR vendor interviews. Table 6 describes themes and descriptions from EHR vendors on the successes, challenges, and resources needed to make the integration of PGHD actionable. Organizational support and readiness to use PGHD in a meaningful way are needed for success. A variety of factors influence the success of PGHD to improve health outcomes and create value. This includes clinical champions, a patient-focused approach, and data and device governance in which PGHD are part of a targeted care delivery model. Other factors include interoperability and economic viability. Challenges arise when a well-resourced plan with all stakeholders is not the approach. Resources such as educational support for clinicians and patients, and technical support for patients are key.

Table 6. EHR vendor interview themes

PGHD Successes and Challenges	Theme	Description
Successes: Factors that contribute to the success of making integration of PGHD actionable	**Organizational support and readiness**	Organizations need to invest and prepare for the use of PGHD. This requires consistent organization-wide processes on how to leverage PGHD, marketing representation to create value for patients, and buy-in across the enterprise.
	Clinical champions	Physicians, nurses, case managers, social workers, and other roles need to advocate and champion the use of PGHD for patient care. Champions must be maintained over time, or interest may fade.
	Robust care delivery model	PGHD need to be tied to clinical focus (e.g., congestive heart failure [CHF], hypertension). This allows for data and devices to be selected that are appropriate for specific clinical outcomes and targeted to the care delivery model allowing patient self- management and clinical decision-making. This permits data governance and protocol development to understand how to act upon the data by patients and providers. Processes need to create value and not increase burden on the care team.

PGHD Successes and Challenges	Theme	Description
	Data governance	PGHD need to be valid, accurate, and well managed with rules to make them useful, timely, interpretable, and effective. Collection and interpretation must be tailored to the clinical focus and population. Protocols and triggers need to be incorporated into the EHR to encourage patient self-management and clinician decision making. Data analytics are needed to discern signal from noise. Decisions need to be made as to how data will be analyzed over time and in a tailored time window. Data density, when data are missing or too frequent, requires protocols for how to deal with changes in data frequency over time. Data need to be aggregated across sources and visualized in a dashboard with clinical decision support tools.
	Device governance	Devices could be a BYOD model, managed by clinics or by a vendor. Devices could be delivered as a kit that collects data specific to the clinical focus. Multiple devices may be needed but can contribute to complexity. The approach may be influenced by the type of EHR vendor the clinic or health system contracts with.
	Interoperability	Data need to be exchanged seamlessly across geographic boundaries between disparate organizations, systems, and sources. Consistent standards are critical and may include HL7 and FHIR.
	Patient-focused approach	Data and devices need to be useable and appropriate for the target population. The demographics of the patient population need to be considered (e.g., use of iOS or Android, technical literacy, broadband access, physical dexterity).
	Technical support	A fundamental requirement is to provide support for patients across the lifespan in diverse environments. Support ought to be provided by a technical person from the clinic or organization, the device manufacturer, or outsourced. Clinical staff, such as RNs, are not the best fit for this role.
	Economic viability	The use of PGHD needs to be incorporated into the business model of the organization to demonstrate revenue generation or cost savings.
Challenges: Factors that contribute to challenges of making integration of PGHD actionable	**Lack of regulations and industry standards**	Data need to be standardized across the industry. There are disparities in EHRs, devices, and applications. Not all EHR vendors use consistent standards, such as FHIR. Standards for some EHR vendor platforms are not as mature as others.
	Poor data governance	Protocols are needed to create value from PGHD. Analysis of disparate data sources and determining how and when to act upon data are critical. Organizations may struggle with the legality of PGHD.

PGHD Successes and Challenges	Theme	Description
	Patient technology hurdles	Technical and data literacy must be considered for the target population. Access to broadband internet, particularly in rural locations, may be a hurdle. Patients need to be proficient with how to use devices, particularly multiple devices, which can be amplified for patients who have multiple chronic illnesses and who are often older.
	Manual data entry and lack of analytics	Automated data entry is needed when possible. Resources should be dedicated so that data are programmed to be automatically ingested by software to create meaning and value for patients and clinicians.
	No care delivery model	PGHD cannot live in a vacuum. Responsibility for the data is needed and it needs to be tied to health outcomes to select the most appropriate data type and device in order to create value. There remains a lack of national standards around care models for PGHD.
Resources needed to support PGHD	**Clinical application and data processes**	Organizational investment is needed to develop use cases for PGHD in a variety of care models. Data procedures include governance, protocols, and processes that guide the use of PGHD for clinical decision making and patient self-monitoring that meet patient outcome, regulatory, and legality needs.
	Clinical workflow capacity	Clinicians need dedicated time to incorporate PGHD into their clinical workflow.
	Educational support for patients and providers	Education and training need to be provided to all end users to understand the benefits and limitations to PGHD.
	Technical support	Technical support to patients across the lifespan in diverse environments provided by a technical person.

Vendors described that most clients collect PGHD through surveys that are offered through their patient portal. This may include information being collected before or between clinic visits. COVID-19 has increased use of surveys to collect information on symptoms, exposure, and testing. Less common is the use of remote monitoring devices.

The use of remote monitoring devices is offered in a variety of ways, depending on the relationship between ambulatory care clinics and the EHR vendor. The vendor may offer devices in a 'kit model,' where the patient receives a suite of devices tethered toward a clinical target area. For example, patients with hypertension may receive a Bluetooth-enabled blood pressure monitor and in-home wireless scale. Similar kits for COVID-19 symptoms are on the rise for temperature, blood pressure, and pulse oximetry remote monitoring. The rise of the Hospital at Home model is a similar and quickly growing care delivery model that is accelerating the use of PGHD integration. Third-party vendors may offer device kits and provide tech support. These are negotiations between the clinic or health system, EHR vendor, and device vendor.

Decisions to implement are driven by the clinical side, while the EHR and device vendor provide development support. Development, implementation, and testing usually takes 6-12 months, though prioritized topics can have accelerated timelines. Development and development costs are unique to the EHR vendor and their relationship with the clinics. This influences the way in which PGHD is financed, which could be by per-patient transaction.

EHR vendors stated their systems undergo full security assessments. Data are more protected once they come into the EHR ecosystem, which could be through a patient portal or via API from a device company. Security with devices and their associated apps needs to be worked out with the respective device companies. Risk is held on the patient's side before data cross into the EHR, and data may not fall under privacy and security regulations. Patients should be encouraged to use standard security approaches, such as user authentication, and to limit health information exchange with third-party apps. Limited regulations around PGHD and consumer-based devices makes this an ongoing challenge.

Policy, Regulation, and Reimbursement

Even though Americans are now transmitting their personal data via the internet at an exponentially higher rate than in the past, the legislative patchwork at the Federal level governing data privacy is complex and incomplete. While some Federal laws and regulations address aspects of data privacy and reimbursement related to the use of PGHD, significant gaps remain. Policymakers may want to consider supportive policies pertaining to cybersecurity in the transfer of data from devices into EHRs, and a comprehensive payment policy that incentivizes clinicians to use PGHD to facilitate actionable clinical decision-making. An effective payment policy will need to help ambulatory care settings overcome the technical and workflow challenges associated with integration of PGHD into their EHRs as well as optimize best practices in patient engagement and chronic care management.

Data Privacy and Security. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) includes the most relevant provisions for healthcare providers governed by HIPAA. Under HIPAA, healthcare providers must treat protected health information (PHI) according to rules set forth in several HHS regulations known as the "Privacy Rule," the "Security Rule," and the "Breach Notification Rule."[56]

The HIPAA Privacy Rule establishes safeguards to protect PHI and patient rights to understand how their data may be used and shared. With respect to sharing, HIPAA's privacy rules generally prohibit covered entities from using or sharing PHI with third parties without patient consent, unless such information is being used or shared for treatment or payment, among other exceptions.[57] Additional Federal guidance is needed to determine whether these provisions would require ambulatory care settings to obtain a patient waiver before integrating PGHD into a patient's EHR. Distinct requirements concerning consent forms may also pertain to children who participate in an ambulatory care setting's PGHD program. The **Children's Online Privacy Protection Act (COPPA)** may require providers to obtain parental or guardian permission to collect identifiable information from patients under the age 13.[58]

Data sharing with vendors. Ambulatory care settings may want to pay particular attention to data security when working with third-party vendors who capture and analyze a patient's data before providing patient summary reports to providers. The ONC reports that before reaching the EHR, PGHD "may be at risk for security breaches because they are not subject to the same security regulatory framework as providers who are regulated by HIPAA. Concerns include insecure points of data collection and insecure data movement that potentially expose the device or the clinician's information system to pollutants, such as malware. There is growing potential for risks related to unauthorized access, including cyber threats."[59] The Security Rule requires covered entities to maintain administrative, physical, and technical safeguards to prevent threats or hazards to the security of electronic PHI. The technical safeguards must include transmission security measures designed to "guard against unauthorized access to electronic PHI that is being transmitted over an electronic communications network." These measures must have "integrity controls" to ensure the electronically transmitted PHI is "not improperly modified without detection until disposed of" and mechanisms "to encrypt electronic protected health information whenever deemed appropriate."[60] Ambulatory care settings intending to support the movement of patient data into their EHRs should work with their information technology and security experts to ensure safe movement of these data.

PGHD, like all PHI, is at risk for security breaches. These data can be at particular risk during transfer using devices connected to the internet.[4] Ambulatory care settings should have robust practices in place that minimize risk of data security threats. For support in establishing robust organization-wide cybersecurity practices, the Health Sector Coordinating Council (HSCC), in partnership with the U.S. Department of Health and Human Services, produced "Health Industry Cybersecurity Practices (HICP): Managing Threats and Protecting Patients." This practical guide includes volumes, resources, and toolkits to support small, medium, and large healthcare organizations establish robust cybersecurity practices.[61]

Patients engaging in PGHD may have a limited or incorrect understanding of when data about their health is protected by law, and when it is not. For example, they may incorrectly think HIPAA provides standards for privacy and security in all contexts, where no such universal protections exist. The more information collected and transferred, the greater the cybersecurity threat. Thus, individual users may make avoidable mistakes that could increase cybersecurity threats related to PGHD. When selecting vendors with whom to partner, ambulatory care settings should consider which can ensure the data security and privacy for their patients and their settings.

Proposed CMS rule regarding the exchange of health data with patients and payers.[62] CMS' proposed rule, December 10, 2020, strives to improve the electronic exchange of health data among payers, providers, and patients, and streamline processes related to prior authorization. In addition to proposing new requirements on payers regarding prior authorization and the exchange of health data, the proposed rule would impose new methods for enabling patients and providers to control sharing of health information, place new requirements on the exchange of behavioral health information, reduce the use of fax machines for healthcare data exchange, and accelerate the adoption of standards related to social risk data. Ambulatory care settings will want to look for the forthcoming Final Rule to ensure that their programs align with any new requirements.

Reimbursement for PGHD. Public and private payers are increasingly using payment to support use of PGHD for remote patient monitoring. However, what is covered and for what amount varies significantly by payer and geography.

Medicare, our Nation's Federal program covering healthcare services for individuals 65 and older and certain individuals with permanent disabilities, covers certain activities related to PGHD. As of 2018, Medicare-qualifying clinicians can seek reimbursement using CPT Code 99091 for time spent on collection and interpretation of health data generated by a patient remotely, digitally stored, and transmitted to the provider, at a minimum of 30 minutes of time in a 30-day period per patient.[63] Since 2015, qualifying clinicians can seek Medicare reimbursement for Chronic Care Management Services conducted on behalf of certain Medicare beneficiaries with multiple chronic conditions and for transitional care programs.[64] Incentive payments that can be applied to PGHD review are also available through Medicare's Physician Payment System[64] that rewards clinicians who meet certain performance metrics under the Quality Payment Program (created by the Medicare Access and CHIP Reauthorization Act of 2015 [MACRA]).[65]

Medicaid, a joint Federal-State program that finances the delivery of primary and acute medical services and long-term services and supports to diverse low-income populations, provides coverage for remote patient monitoring in many States. According to the Center for Connected Health Policy (CCHP), the federally designated National Telehealth Policy Resource Center under the Federal Telehealth Resource Center Program, 21 State Medicaid programs offer reimbursement for remote patient monitoring as of fall 2020.[66] Because reimbursement policies vary significantly by State, ambulatory care settings eager to obtain Medicaid reimbursement should check with their State Medicaid representatives and review CCHP's State Telehealth Laws and Reimbursement Policies, which is updated periodically.[66]

Many private payer insurance plans also reimburse for PGHD used for remote patient monitoring services; however, Federal law does not require these payers to do so. As a result, significant variation in coverage rules are also found with these payers. Any reimbursement program established by an ambulatory care setting will need to navigate significant variation across these payers to compile its unique patchwork reimbursement program.

New value-based payment models create incentives for use of PGHD. New reimbursement models, such as alternative payment models, are shifting from payment for individual services to payment for episodes of care, overall care, and patient outcomes. These new payment models can provide clinicians with great flexibility in care delivery, enabling them to establish remote patient monitoring initiatives to minimize the need for face-to-face encounters and emergency room visits. As participation among ambulatory care settings in value-based payment models grows, so too will opportunities for ambulatory care settings to engage in PGHD initiatives.

Chapter 4. Summary of Results

Scoping Review – the Evidence

Consistent with previously reported findings by Tiase et al., there are limited studies on the integration of PGHD in ambulatory care practices. Nevertheless, the rate of expansion of these studies in recent years is promising [Table 1]. In one year, through October 2020, 14 additional studies that met similar inclusion criteria reported on the usage of PGHD that integrated into the EHR.

Given that few studies have been published on the topic of PGHD integration, much work remains to be done. First, only three studies focused on the integration process of PGHD in the EHR. This left us having to glean information from the remaining studies that were deemed relevant. Furthermore, few studies truly evaluated patient healthcare outcomes in a randomized controlled fashion. This, too, represents an important gap in the literature. While we may intuit the benefits of PGHD collection and integration in the EHR, much remains to be evaluated with respect to the costs/benefits of source of data collection, the influence of PGHD alert systems on provider adherence to guidelines, and the specific role that PGHD types have on patient outcomes.

Our findings also demonstrated a balance of studies on the use of biometric data and survey questionnaires. Only one group reported on the use of free-text histories.[67] Patients had a positive experience with this approach. Nevertheless, there was limited information on the providers' utilization of data collected from free-text reports. As the success of PGHD use is highly dependent on provider adoption, the data need to be formulated in a manner that maximizes the ease of use for providers. As such, while we believe free-text patient reports will invariably have a space in PGHD, likely provider adoption will be higher for discrete data elements.

Discrete data elements are collected for biometric data and PRO measures. Of the 18 studies that reported capturing biometric data, we found that many involved patient self-documentation of biometric data. For instance, Moore et al. had patients manually input home-measured blood glucose, blood pressure, or pedometer recordings.[68] Others collected the data passively from the patients' devices. These instances required the use of third-party applications to collect device data (predominantly Apple HealthKit), which integrated data into the EHR.

While there has been general sentiment on the benefits of passive data collection, it is unknown whether a patient's active input of PGHD could contribute to improving health outcomes. Such questions around the psychological implications of increased patient awareness of collected biometric data due to manual collection of the data still needs exploration. Passive data collection also raises the question of data collection and transfer frequency. There seemed to be stark variation in biometric data collection frequency from the order of seconds[36] to daily or less frequent.[24,69,70] There seems to be a need for evaluation of the clinically meaningful needs for data collection compared to potential operational and research interest in more data. Such a discussion needs to consider the ethics of appropriate patient consent for data collection and communication of the data use. As PGHD tools are developed and utilized in healthcare, the field needs to consider protections that ensure that collected PGHD are necessary for clinical care. Certainly, any alteration to data type and collection frequency for research purposes needs patient consent with alternatives to participation offered.

Frequency of data transfer raises its own challenges. One study reported that high-volume data transfer resulted in patient portal app errors, solved by batched data upload.[71] This raises security concerns around data storage on user device or third-party cloud platforms.The use of PROs was also high amongst our included studies. PROs are excellent sources for patient healthcare information. While studies evaluated different PROs, we were able to extract general PRO themes. Studies focused on quality of life/function measures, symptom severity measures, and medication utilization. We did not directly assess findings on differential patient or provider usage in one study as compared to another, but such information needs to be assessed in future analysis. Understanding whether patients or providers underutilize particular data metrics, and why they underutilize such metrics, could help support the selection and adaptation of the most appropriate PRO measures. Selection considerations may include PRO length or completion time. From a user-centered design, survey lengths have previously been noted to significantly impact survey completion rates.[72] One proposed method to improving survey completion time is the utilization of computerized adaptive testing (CAT). However, only two studies, stemming from the same institution, reported utilizing CAT.[73,74] We suspect that CAT utilization remains low because of the lack of validated CAT PROs. This means that groups such as the aforementioned would need to also face the challenge of developing and validating their own CATs.[73,74] While we did not directly assess whether the PROs utilized were validated, we believe it is vital to use validated instruments to avoid group data underrepresenting, overrepresenting, or not reporting the communicated outcome. Further, use of unvalidated tools can reduce clinician buy-in for the use of PGHD in the augmentation of clinical care.

Best Practices

There were several themes that appeared to contribute to group success within our review. Amongst these, early stakeholder involvement contributes to project success and clinician adoption. Some clinicians reported skepticism and concern around the use of PGHD, with many focusing on the impact of PGHD integration on increasing workload. Early inclusion of clinician stakeholders, however, mediates these concerns by ensuring system selection of relevant PGHD tools that improves care outcomes and efficiency. Furthermore, early inclusion of clinician stakeholders increases data usage. In part, this means the assignment of a clinician champion who serves to interface between the project build team and clinicians. Stakeholder involvement should extend to the care team, management, quality improvement specialists, and patients.

Direct integration of PGHD in the patient portal is a common approach used by many of the evaluated studies. Collection of PGHD through the patient portal limits multiple elements of data collection complexity, including user authentication of input data, given that only patients input their data directly into the patient portal. Furthermore, this limits the build complexity by not requiring interoperability between an external app and the EHR. Nevertheless, at present this approach only works for manual input of user data. In the case of passively collected biometric data, the data must still be collected on a third- party platform and secondarily integrated in the EHR. While users seemed to prefer inputting data on their phone apps, some reported preference for web apps on their computer, and others preferred pen and paper. Offering each of these as an option for data collection (particularly for PROs) takes into account not only user preference, but also user technology access and digital health literacy.

Operationalizing the use of PGHD also seemed an important practice across many of the included studies. That meant the study teams needed to develop workflows for practical interventions based on the collected data. It also meant they needed project-specific coordinators. These coordinators functioned to evaluate PGHD input by patients, review by providers and, in some instances, arbitrators of PGHD- related alerts. Based on our review, this support role seemed important to limiting the potential increased burden of PGHD use on providers. As PGHD is incorporated in the EHR in increasing quantities, however, clarity will need to be developed about the training for such a support role and the extent to which these coordinator roles could span across different PGHD types.

Finally, a best practice noted by our group was the review of project success and active alteration of design to meet rising challenges. Reminiscent of the Plan-Do-Study-Act (PDSA) cycle, many groups utilized this cyclic approach due to inevitable challenges that arose during project development. For instance, Marquard et al. specifically reported that in anticipation of patient-facing technical challenges, they designed a preliminary study of 26 patients, analyzing and logging technical issues that arose, adapting their project to the noted challenges.[75] We believe that in order for integrated PGHD projects to succeed, a similar approach that evaluates project challenges and adapts to them is necessary. This requires that stakeholders develop assessments of the elements deemed necessary for project success. That includes evaluation of 1) user experience including the patient, provider, coordinator, and other stakeholders; 2) hardware function; 3) software security; 4) data integrity; and 5) evolving regulatory policies influencing the project.

Concerning Gaps

The majority of included studies are based out of academic medical centers and utilize the Epic EHR. Both are not representative of the standard ambulatory practice. Equipoise assessments of the integration of PGHD in group and individual private practices (which make up the majority of primary care practices in the USA[76]) need to be conducted.

EHR Vendor Survey and Interviews

Feedback from the EHR vendors highlighted the evolution that PGHD is undergoing as tools for patient care delivery. Over the past decade, PGHD use has steadily increased as access to the internet and smartphones have proliferated. Pathways for data from devices or surveys to be brought securely into the EHR are increasing. Geographic barriers are falling and allowing for PGHD to be transmitted in near real- time from environments that patients spend more of their lifetime in. There are a variety of models that can be adopted in the integration of PGHD. Ambulatory care clinics are able to partner with EHR vendors, and other partner vendors such as data aggregators (e.g., Validic, Raziel Health) or device companies (e.g., Omron, Qardio, Withings) to build frameworks and support for PGHD to be used for a variety of clinical needs.

Vendors reported using iOS to pull in a variety of PGHD to their EHRs and largely support the Apple ecosystem. Android is not as well supported, though. This is a concern, given that approximately 38% of the U.S. market is Android.[77] Few vendors allow for multi-language support, with only one reporting to allow for data to be ingested in Spanish. These factors have the potential to contribute to disparities in healthcare access among under-served populations.

There are disparities in EHRs, devices, and applications. Vendors discussed the lack of regulations and enforced standards around PGHD. While standards such as FHIR are encouraged, they are not used exclusively. Fortunately, new interoperability rules from ONC will boost the exchange of data through APIs and FHIR standards.

Table 6 describes a variety of factors that contribute to the successes and challenges of integrating PGHD. Vendors stressed the importance of organizations investing in robust care models, secure and interoperable technology, data and device governance, and providing resources, technical support, and planning to bring value to the use of PGHD.

Reports, Guides, and Policies

A variety of implementation guides and resources are available on websites from government agencies, professional organizations, and nonprofits. Table 4 presents documents that cover a variety of aspects important to the selection, integration, and use of PGHD for clinical care in ambulatory care settings.

Many decisions and aspects are important to the use of PGHD that range from clinical to technical and legal. The policy landscape surrounding PGHD evolves quickly, and it is important for ambulatory care clinics to be familiar with topics ranging from reimbursement to FDA clearance for devices.

Recommendations

We present a thematic summary of recommendations (Table 7) from the scoping review (Tables 1, 2 and 3), reports (Table 4), policies, and data collected from the EHR vendors (Tables 5 and 6). Recommendations from this environmental scan were reviewed by the TEP and will inform the development of a practical guide for ambulatory care providers as they approach the integration of PGHD.

Table 7. Recommendations for the implementation of PGHD into EHRs

Recommendation	Details
1. **Develop a Strategy or Blueprint**	• Plan for a phased approach – explore, prepare, implement • Engage leadership • Conduct a stakeholder analysis and needs assessment • Define success and create goals • Assess the business case, including reimbursement and savings opportunities • Evaluate the EHR vendor capabilities and devices along with 3rd-party vendors, as relevant
2. **Identify Champions and Early Adopters**	• Identify clinical champions – physicians, nurses, case

Recommendation	Details
	managers, and others • Take a team approach involving all stakeholders (e.g., clinicians, staff, IT, patients) • Identify clinical sites to serve as early adopters
3. Tie PGHD to a Care Delivery Model	• Tie to a clinical focus (e.g., hypertension, CHF) • Establish quality monitoring • Select the PGHD and then tools (questionnaires, biometrics, devices) • Understand regulatory requirements such as those from ONC and CMS
4. Design the Workflow	• Prepare a care team • Partner with the patient • Develop consistent processes across the institution on the use of PGHD • Processes should not increase burden on the care team
5. Use a Patient-Focused Approach with a Health Equity Lens	• Be inclusive across diverse patient population characteristics • Address health literacy and technical literacy • Address capability to use a tool (e.g., dexterity, vision, voice) that may be influenced by age, culture, illness, or chronic condition • Assess access to broadband and internet connectivity • Assess smartphone operating system of the target population: iOS vs. Android • Engage patients over time – motivate and incentivize
6. Leverage a Robust Technology Architecture	• Use interoperability standards such as FHIR • Data should exchange across disparate organizations, systems, and sources • Integrate data views for clinicians and patients • Invest in security and privacy that meet HIPAA requirements and protect patient data
7. Create Data Governance	• PGHD need to be valid, accurate, and well-managed to make it useful, timely, and effective • Collection and interpretation must be tailored to the clinical focus and patient population • Automation, to the extent possible, is key • Create protocols to act upon PGHD for patient self-management and clinical decision making • Synthesize data across multiple sources • Incorporate data analytics to discern signal from noise • Make decisions on how to analyze data over time in tailored 'time windows' • Address data density – data missing, too frequent, and changes in frequency over time • Visualize data in a dashboard (within the EHR is preferable)
8. Create Device Governance	• Decide who manages devices – clinics, vendors, or BYOD model • Review the contract with the EHR and device vendor

Recommendation	Details
	• Review FDA regulatory requirements • Include devices that are tied to the clinical focus as a kit • Be mindful that, while multiple devices may be needed, complexity will increase for all users
9. Provide Guidance and Education to Stakeholders	• Train staff • Provide accessible educational materials to staff and patients • Market the benefits of PGHD inside and outside the organization • Teach patients how to use devices and interpret PGHD to manage conditions.
10. Implement and Adapt through Iteration	• Pilot test • Enroll patients, and set clear expectations • Obtain feedback from stakeholders, and improve processes through iteration • Evaluate new PGHD and tools • Review new practice guidelines, liability, privacy, and security standards
11. Evaluate Against Metrics and Goals	• Assess against metrics: patient numbers, reductions in no-shows, clinical outcomes, satisfaction • Measure against goals • Drive economic viability for a sustainable business model
12. Plan for Maintenance and Scaling	• Promote success throughout the organization • Maintain or engage new clinical champions • Budget and secure financing for growth
13. Provide Technical Support	• Provide dedicated technical support for staff and patients and families across the lifespan • Support can be provided by the clinic/health system, device manufacturer, or outsourced • Clinical staff, such as RNs, are likely not the best fit for this role

Chapter 5. Discussion

The Rise of Health at Home

The U.S. healthcare system is in a transitional period. Data traditionally collected in a clinic or hospital setting are now able to be collected in everyday environments of patients. Current primary care models often revolve around series of episodes rather than functioning as a continuum.[78] The ability to transition from collecting discrete episodes of data in a clinic setting where patients spend little "life" time, to a model to where patients collect data throughout the day where they "live," provides opportunities to deliver more personalized care. Capturing these data facilitates patients and clinicians to better understand and predict illness dynamics and to develop approaches to improve health outcomes and deliver personalized care when it is most needed:[78] at home.

Our formal scoping review provides evidence and examples from peer-reviewed literature on the integration of PGHD into EHRs across a variety of care delivery models in ambulatory care settings. This growing published evidence is reflected in the feedback from EHR vendors. Vendors described a developing healthcare landscape in which they partner with healthcare institutions to leverage PGHD to improve health outcomes and improve care coordination. To create value from PGHD, however, requires investment, commitment, and an understanding of many variables that influence the success and challenges of PGHD to improve patient outcomes, care coordination, quality, and cost-effectiveness.

COVID-19 and the Rise of Telehealth

The COVID-19 pandemic accelerated the use of digital health. As social distancing measures were enforced, care providers were motivated to collect data from patients remotely. While initially focused on telehealth models of care using video visits, as the pandemic unfolded, other models of care that integrate PGHD grew. As the investment in technology infrastructure, easing of regulatory hurdles, and opportunities for reimbursement occurred, avenues to leverage PGHD as part of formal care delivery models are on the rise. Hospital-at-home programs are one example of a growing market where patients collect data in their home, and a team of clinicians monitor data and provide care as appropriate at a distance or in the home, if needed. While these programs began prior to the pandemic, pressure to collect data at a distance fueled the need for new and safe approaches to care delivery. While promising, adoption of health IT systems has its problems, including clinician and patient burden due to design and implementation issues that have resulted in poor usability and workflow integration challenges.[1] The ONC Cures Act Final Rule has provided much-needed regulation, structure, and incentives to help alleviate challenges and support seamless and secure access, exchange, and use of electronic health information.[79]

As COVID-19 tested health-system capacity, virtual care and remote monitoring grew in the spotlight to deliver care amid social distancing efforts to prevent virus spread.[80] Regulatory and reimbursement barriers fell, and investment grew for telehealth facilitating remote care delivery. The FCC COVID-19 Telehealth Program, for example, provided $200 million in funding as part of the Coronavirus Aid, Relief, and Economic Security (CARES) Act to expand video-visit capacity.[81] This first round of the program supported the use of telehealth to 540 healthcare programs across the United States. The FCC's Connected Care Pilot Program provides up to $100 million to improve broadband connectivity in underserved parts of the country where access to care is limited or hindered.[82]

While telehealth programs expanded, EHR vendors described how COVID-19 slowed implementation of projects nationally for PGHD in the beginning of the pandemic. At the same time, the rapid shift to remote care delivery promoted pockets of innovation in the use of PGHD for monitoring COVID-19- positive patients. One such example was a partnership between Cleveland Clinic and Epic. As reported by news media, they developed a 14-day interactive care plan through the patient portal where patients can enter symptoms, temperature, and oxygen at home, while clinicians monitor them from afar.[83]

As we enter the next phases of the pandemic with vaccine distribution, the implementation of PGHD in ambulatory care settings is gaining speed. Healthcare systems are implementing new models of care delivery, such as hospital-at-home programs, as reimbursement for remote care delivery becomes more certain. The University of Michigan deployed a patient-monitoring at-home kit for patients positive for COVID-19.[84] The kit includes a Bluetooth-enabled blood pressure cuff, thermometer, and pulse oximeter tethered to a tablet that sends vitals and symptoms data two to four times per day to RNs and MDs for monitoring. If data are abnormal, an RN is alerted, in which case they conduct a video visit and escalate if appropriate to an NP, PA, or MD. With a focus on CHF, cirrhosis, and other comorbid conditions, preliminary findings demonstrate a decrease in readmission rates and ED utilization pre- versus post- utilization.

PGHD and Ambulatory Care

A growing number of telehealth vendors provide technology-enabled services that integrate PGHD.[85] Banner Health, for example, partners with Cerner and Xealth to simplify how clinicians prescribe digital health for telehealth and remote patient monitoring. Clinicians are able to prescribe digital therapeutics, smartphone, and internet apps as tools that connect with the EHR for chronic disease management, behavioral health, maternity care, and surgery prep.[86]

Results from the environmental scan reflect this importance to incorporate PGHD in tailored care delivery models. A team approach across medicine, nursing, pharmacy, population health, and other health professionals is needed. In particular, case managers and nurses are well suited to be significant stakeholders in the management of PGHD. A team approach that uses nurse-managed protocols may have positive effects on the outpatient management of adults with a range of chronic conditions.[87] A number of studies demonstrate leveraging PGHD in patient populations, including those with CHF[88], acute coronary syndrome,[39] dermatology[89], oncology,[33] and heart rate data for cardiologist review.[36]

Semantic Interoperability

The ability for computers to exchange data with shared meaning allows for accurate and reliable communication. When a common vocabulary is achieved (also known as interoperability), data and information can be exchanged across networks using mutually accepted protocols. This fosters a number of healthcare initiatives for quality improvement, population health management, and notably the use of PGHD for patient care delivery and clinical decision making. Given the diversity of data sources from connected devices, PRO surveys, mobile apps, and more, it is critical that standards be used across the industry that allow for interoperable data exchange. Supporting patients through data capture and transfer into EHRs is highly complex. Standardized interoperable data interfaces such as HL7's SMART and FHIR[11] are becoming increasingly important. With the rollout of new ONC interoperability rules requiring healthcare providers who receive CMS payments to use FHIR-compatible apps for patient data, adoption will likely accelerate.

Many institutions have demonstrated success with leveraging FHIR to integrate PGHD into their EHRs for patient care delivery.[38,39] This allows for the transferability and adoption of PGHD to other health systems and ambulatory care clinics using a common framework. Interviews with EHR vendors stressed the importance of adopting industry-wide standards such as FHIR to prevent "reinventing the wheel." Nevertheless, FHIR is not standardized across the industry, and not all vendors reported using FHIR. Fortunately, FHIR interoperability standards are gaining traction, and frameworks continue to be developed such as SMART Markers, for example. SMART Markers is a new software framework for capturing PGHD that allows innovators to create custom versions of apps for patients and clinicians.[90] SMART Markers supports a number of data types from surveys and device-recorded platforms.[90] A number of reports, including those from the AMA, PCORI, ONC, and Continua (Table 4) provide guidance on using interoperability standards such as FHIR in the selection, collection, and use of PGHD.

Security and Privacy

The importance of security and privacy cannot be overstated. The HIPAA Security Rule establishes "national standards to protect individuals' electronic personal health information that is created, received, used, or maintained by a covered entity. The Security Rule requires appropriate administrative, physical, and technical safeguards to ensure the confidentiality, integrity, and security of electronic protected health information."[91] Ambulatory care clinics and the vendors they interface with must have in place physical, network, and process security measures and follow them in order to ensure HIPAA compliance.

Ambulatory care clinics must determine when they are legally responsible for data security and privacy of PGHD. Using a kit model, where devices and tools are provided to patients, gives clinics control over the data flow and may enhance approaches to security and privacy. This is in contrast to relying on a BYOD model where patients use their smartphone or buy a consumer device (e.g., Garmin, iHealth) that may send data to a third-party company or share data with other apps on their phone. Patients should be encouraged to use standard security approaches such as user authentication and to limit health information exchange with third-party apps. Limited regulations around PGHD and consumer-based devices makes this an ongoing challenge.

Data are more protected once they come into the EHR ecosystem, which could be through a patient portal or via API from a device company. While patients should be given education to make informed decisions about data and security, their smartphone is owned by them, and data do not fall under HIPAA regulations prior to entering the clinic's electronic ecosystem. As described in Chapter 3, Ploner and Prokosch[38] present a well-described systems architecture and FHIR-based data model that includes security measures and application flow from patients' smartphones and a public cloud infrastructure.

Health Equity and Health Disparities

While the integration of PGHD into EHRs holds promise to improve self-management, care coordination, quality, and cost-effectiveness, these improvements may be stymied by digital divides and have unintended consequences for health equity.[92] Poverty, poor engagement with digital health tools for some communities, low digital health literacy, and lack of access to broadband are some factors that may influence the potential impact of PGHD in ambulatory care settings.[92] PGHD selection and use require active efforts to be inclusive of diverse patient populations in design and implementation strategies.

Broadband and device access. High-speed internet access, whether through broadband or a smartphone, and device access are fundamental components to consider for patients to benefit from the use of PGHD. However, over 21 million Americans lack broadband access.[93] Over 30% of rural Americans and 60% of healthcare facilities outside metropolitan areas lack broadband access.[94] This has disproportionately affected communities of color in rural areas. Rural counties where a majority of residents are African American have few provider options and are more likely to be completely unserved.[95] Device access is also critical for patient engagement with PGHD. While over 81% of American adults own a smartphone, many people rely solely on their phone for internet access, often in communities of color. Further, smartphone access is divided into two dominant operating systems—iOS and Android. Promoting equitable access to PGHD must be inclusive of both operating systems. EHR vendors responded that they incorporate PGHD into their EHR; all reported connectivity with iOS HealthKit, yet only two reported connectivity with Android/Google Fit (Table 5).

Digital health literacy. Patients must be able to use PGHD and its associated tools. Digital health literacy is an extension of health literacy and is the degree to which a patient is able to obtain, process, and understand digital services and information.[96] Patients need education and empowerment on how to collect PGHD, use devices, and interpret health data over time. Even further, patients need to be able to understand privacy and security implications of using apps and devices, and should be informed as to how their data are being used and where they are going. The ONC rule notes that healthcare institutions could, for example, include a warning identifying an app as untrusted and giving patients the option to reject data access.[97]

Inclusive design. Many patient-facing mobile apps and portals feature inaccessible design features. Many lack focus on culture, literacy and numeracy, which limit the benefits of PGHD and may even worsen inequities.[96] Patients should be included as key stakeholders in the development of care models that incorporate PGHD. This will maximize the potential benefits of PGHD and help ensure that the use of PGHD improves patient outcomes, care coordination, quality, and cost-effectiveness.

Limitations

We note a number of limitations to this environmental scan. Our search results were limited to the English language and did not include in-press or unpublished manuscripts and reports such as technical documentation that may be useful in understanding approaches to the integration of PGHD into EHRs.

Our search and review of reports and guides may have missed noteworthy reports, particularly those from government agencies outside of the United States. The scoping review built upon a review by Tiase et al.[3] in which we used *a priori* codes and themes that may have limited curation of new themes and knowledge generation. The grey literature search was limited to the first 50 results in the Google search engine.

While we attempted to collect data from vendors that serve over 95% of the U.S. ambulatory care market, we were not able to collect data and conduct interviews with all vendors contacted. Lastly, the impact of the COVID-19 pandemic has had a profound impact on the U.S. healthcare industry. Policies, regulations, and the use of PGHD itself is quickly evolving, and information captured in this report is limited to the period of data capture and synthesis.

Future Trends

The use of PGHD for remote monitoring facilitates data-driven care and allows for the development of new care delivery models that allow us to go beyond the traditional brick and mortar clinic model.

Emerging models of care blend telehealth with in-home and in-clinic approaches. Beyond the hospital-at- home model, companies such as Amazon are piloting new models such as Amazon Care that brings healthcare closer to patients' everyday environment. This model allows patients to communicate with providers through a smartphone app in a variety of ways, including video visits, submitting photos, and tracking vital signs and more using connected devices. Moreover, an RN, NP, PA, or MD comes to the patient's home to draw labs, perform physical assessments, and provide care. Medications and supplies are shipped directly to the patient.

Companies, including Walmart, are venturing into the healthcare industry, which may increase healthcare access to underserved populations at lower prices than many large health systems or clinics. Other companies, like Teledoc, which recently absorbed Livongo, are growing players in the digital disease management arena.

Technology continues to mature. As in-home artificial intelligence (AI) such as Amazon Alexa, Siri, and Google Assistant grow, technology-enabled care evolves. These tools, for example, may be ideal for patient populations such as older adults and those with disabilities who can interact with technology using their voice. A variety of approaches are well suited for these voice-based technologies, such as reminding patient to take their medication, report their blood pressure, and receive instructions on how to care for post-surgical wounds. Other exciting opportunities such as AI-based therapy that guides patients through cognitive behavioral therapy using mental health chatbots are on the rise as well.

Critically, though, while these approaches hold promise to improve care delivery and patient outcomes, they must be designed with a health equity lens. To provide benefit to those who are most in need and reach underserved populations, we must be inclusive of diverse patients and select technologies and create processes that promote health equity and reduce health disparities. A range of stakeholders, including physicians, pharmacists, nurses, population health managers, and more are needed in the design process to create value from PGHD and prevent unintended consequences, such as clinician burnout from technological burden.

Conclusion

Capturing PGHD facilitates patients and clinicians to better understand and predict illness dynamics and to develop approaches to improve health outcomes and deliver personalized care. The COVID-19 pandemic accelerated the use of PGHD, as care providers were encouraged to collect data from patients remotely. While promising, adoption of health IT systems has many challenges[1] and the potential to exacerbate health inequities. The ONC Cures Act Final Rule has provided much-needed regulation, structure, and incentives to help alleviate challenges.[79] Nevertheless, more supportive policies are needed.

This environmental scan presents a thematic summary of recommendations from the scoping review, reports, policies, and data collection from the EHR vendors. These recommendations will inform the development of a practical guide on the integration of PGHD for ambulatory care providers.

References

1. Gettinger A, Zayas-Cabán T. HITECH to 21st century cures: clinician burden and evolving health IT policy. *Journal of the American Medical Informatics Association*. 2021.
2. Tiase VL, Hull W, McFarland MM, et al. Patient-generated health data and electronic health record integration: protocol for a scoping review. *BMJ Open*. 2019;9(12):e033073.
3. Tiase VL, Hull W, McFarland MM, et al. Patient-generated health data and electronic health record integration: a scoping review. *JAMIA Open*. 2020.
4. Office of the National Coordinator for Health Information Technology. Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024. 2018; https://www.healthit.gov/sites/default/files/onc_pghd_practical_guide.pdf. Accessed July 18, 2020.
5. Pew Research Center. *Mobile Fact Sheet.* Washington, DC2019.
6. U.S. Food & Drug Administration. Consumer (Medical Devices). 2020; https://www.fda.gov/medical- devices/resources-you-medical-devices/consumers-medical-devices. Accessed October 27, 2020.
7. Insel TR. Digital phenotyping: technology for a new science of behavior. *JAMA : the journal of the American Medical Association.* 2017;318(13):1215-1216.
8. Lewinski AA, Drake C, Shaw RJ, et al. Bridging the integration gap between patient-generated blood glucose data and electronic health records. *Journal of the American Medical Informatics Association*. 2019;26(7):667-672.
9. Dinh-Le C, Chuang R, Chokshi S, Mann D. Wearable health technology and electronic health record integration: scoping review and future directions. *JMIR mHealth and uHealth*. 2019;7(9):e12861.
10. Marx EW, Padmanabhan P. *Healthcare Digital Transformation: How Consumerism, Technology and Pandemic are Accelerating the Future*. CRC Press; 2020.
11. Mandel JC, Kreda DA, Mandl KD, Kohane IS, Ramoni RB. SMART on FHIR: a standards-based, interoperable apps platform for electronic health records. *J Am Med Inform Assoc*. 2016;23(5):899- 908.
12. Centers for Medicare & Medicaid Services. Policies and Technology for Interoperability and Burden Reduction. 2021; https://www.cms.gov/Regulations-and-Guidance/Guidance/Interoperability/index. Accessed February 7, 2021.
13. Reading MJ, Merrill JA. Converging and diverging needs between patients and providers who are collecting and using patient-generated health data: an integrative review. *Journal of the American Medical Informatics Association*. 2018;25(6):759-771.
14. Hollander JE, Carr BG. Virtually perfect? Telemedicine for COVID-19. *New England Journal of Medicine*. 2020;382(18):1679-1681.
15. Nouri S, Khoong EC, Lyles CR, Karliner L. Addressing equity in telemedicine for chronic disease management during the Covid-19 pandemic. *NEJM Catalyst Innovations in Care Delivery*. 2020;1(3).
16. Neuendorf KA. The Content Analysis Guidebook. Los Angeles. In: CA: Sage Publications;

2017.
17. Sorondo B, Allen A, Bayleran J, et al. Using a patient portal to transmit patient reported health information into the electronic record: workflow implications and user experience. *eGEMs*. 2016;4(3).
18. Young HM, Miyamoto S, Dharmar M, Tang-Feldman Y. Nurse coaching and mobile health compared with usual care to improve diabetes self-efficacy for persons with type 2 diabetes: randomized controlled trial. *JMIR mHealth and uHealth*. 2020;8(3):e16665.
19. Bae YS, Kim KH, Choi SW, et al. Information technology–based management of clinically healthy COVID-19 patients: Lessons from a living and treatment support center operated by Seoul National University Hospital. *Journal of medical Internet research*. 2020;22(6):e19938.
20. Coenen S, Nijns E, Weyts E, et al. Development and feasibility of a telemonitoring tool with full integration in the electronic medical record: a proof of concept study for patients with inflammatory bowel disease in remission on biological therapy. *Scandinavian journal of gastroenterology*. 2020;55(3):287-293.
21. Mammen JR, Schoonmaker JD, Java J, et al. Going mobile with primary care: smartphone- telemedicine for asthma management in young urban adults (TEAMS). *Journal of Asthma*. 2020:1-13.
22. Ancker JS, Mauer E, Kalish RB, Vest JR, Gossey JT. Early adopters of patient-generated health data upload in an electronic patient portal. *Applied clinical informatics*. 2019;10(02):254-260.
23. Girgis A, Durcinoska I, Arnold A, Delaney GP. Interpreting and acting on the PRO scores from the patient-reported outcomes for personalized treatment and care (PROMPT-Care) eHealth system. *Medical care*. 2019;57:S85-S91.
24. Bloom P, Wang T, Marx M, et al. A Smartphone App to Manage Cirrhotic Ascites Among Outpatients: Feasibility Study. *JMIR medical informatics*. 2020;8(9):e17770.
25. Graetz I, Anderson JN, McKillop CN, Stepanski EJ, Paladino AJ, Tillmanns TD. Use of a web-based app to improve postoperative outcomes for patients receiving gynecological oncology care: a randomized controlled feasibility trial. *Gynecologic oncology*. 2018;150(2):311-317.
26. Lavallee DC, Lee JR, Austin E, et al. mHealth and patient generated health data: stakeholder perspectives on opportunities and barriers for transforming healthcare. *Mhealth*. 2020;6.
27. Abdolkhani R, Gray K, Borda A, DeSouza R. Patient-generated health data management and quality challenges in remote patient monitoring. *JAMIA open*. 2019;2(4):471-478.
28. Austin E, Lee JR, Amtmann D, et al. Use of patient-generated health data across healthcare settings: implications for health systems. *JAMIA open*. 2020;3(1):70-76.
29. Adler-Milstein J, Nong P. Early experiences with patient generated health data: health system and patient perspectives. *Journal of the American Medical Informatics Association*. 2019;26(10):952-959.
30. Cohen DJ, Keller SR, Hayes GR, Dorr DA, Ash JS, Sittig DF. Developing a model for understanding patient collection of observations of daily living: A

qualitative meta-synthesis of the Project HealthDesign Program. *Personal and ubiquitous computing.* 2015;19(1):91-102.

31. Cohen DJ, Keller SR, Hayes GR, Dorr DA, Ash JS, Sittig DF. Integrating patient-generated health data into clinical care settings or clinical decision-making: lessons learned from project healthdesign. *JMIR human factors.* 2016;3(2):e26.
32. Bachmann JM, Posch DR, Hickson GB, et al. Developing an Implementation Strategy for Systematic Measurement of Patient-Reported Outcomes at an Academic Health Center. *Journal of Healthcare Management.* 2020;65(1):15-28.
33. Wintner LM, Sztankay M, Riedl D, et al. How to implement routine electronic patient- reported outcome monitoring in oncology rehabilitation. *International Journal of Clinical Practice.* 2020:e13694.
34. Stover AM, Stricker CT, Hammelef K, et al. Using stakeholder engagement to overcome barriers to implementing patient-reported outcomes (PROs) in cancer care delivery: approaches from 3 prospective studies. *Medical care.* 2019;57:S92-S99.
35. Shaw R, Stroo M, Fiander C, McMillan K. Selecting Mobile Health Technologies for Electronic Health Record Integration: Case Study. *Journal of Medical Internet Research.* 2020;22(10):e23314.
36. Pevnick JM, Elad Y, Masson LM, Riggs RV, Duncan RG. Patient-Initiated Data: Our Experience with Enabling Patients to Initiate Incorporation of Heart Rate Data into the Electronic Health Record. *Applied Clinical Informatics.* 2020;11(04):671-679.
37. Moore SL, Fischer H, Davidson AJ, et al. Engaging disadvantaged patients in sharing patient generated health data and patient reported outcomes through health information technology. *Agency for Healthcare Research and Quality.* 2021.
38. Ploner N, Prokosch H-U. Integrating a Secure and Generic Mobile App for Patient Reported Outcome Acquisition into an EHR Infrastructure Based on FHIR Resources. *Studies in health technology and informatics.* 2020;270:991-995.
39. Hur S, Lee J, Kim T, et al. An Automated Fast Healthcare Interoperability Resources-Based 12-Lead Electrocardiogram Mobile Alert System for Suspected Acute Coronary Syndrome. *Yonsei medical journal.* 2020;61(5):416.
40. Buzaglo JS, Stepanski E, Joiner M, et al. Using an ePRO tool to help meet quality metrics in a clinical oncology practice. In: American Society of Clinical Oncology; 2019.
41. Treadwell JR, Reston JT, Rouse B, Fontanarosa J, Patel N, Mull NK. Automated-Entry Patient- Generated Health Data for Chronic Conditions: The Evidence on Health Outcomes. *Agency for Healthcare Research and Quality.* 2021.
42. American Medical Association. *Telehealth Implementation Playbook.* 2020.
43. Personal Connected Health Alliance. *Continua Design Guidelines.* 2019.
44. Personal Connected Health Alliance. Usability and Design Features for the Aging Population in Connected Health. 2019.
45. US Food and Drug Administration. Policy for Device Software Functions and Mobile Medical Applications. 2019.
46. Humboldt Institute for Internet and Society. *The futures of eHealth.*

Social, ethical and legal challenges. 2019.
47. Mahendraratnam N, Silcox C, Mercon K, Kroetsch A, Romine M, Harrison N. Determining Real- World Data's Fitness for Use and the Role of Reliability.(2019). In.
48. Cortez A, Hsii P, Mitchell E, Riehl V, Smith P. *Conceptualizing a data infrastructure for the capture, use, and sharing of patient-generated health data in care delivery and research through 2024: Practical guide.* 2018.
49. Cortez A, Hsii P, Mitchell E, Riehl V, Smith P. *Conceptualizing a data infrastructure for the capture, use, and sharing of patient-generated health data in care delivery and research through 2024: Whitepaper.* 2018.
50. American Medical Association. *Digital Health Implementation Playbook.* 2018.
51. eHealth Initiative. *Leveraging Patient Generated Health Data to Improve Outcomes and Decrease Cost.* 2018.
52. US Department of Health and Human Services. *Health Industry Cybersecurity Practices: Managing Threats and Protecting Patients.* 2018.
53. Association AMI. Redefining our Picture of Health: Towards a Person-Centered Integrated Care, Research, Wellness, and Community Ecosystem: A White Paper of the 2017 AMIA Policy Invitational. *Washington, DC: American Medical Informatics Association.* 2018.
54. Snyder C, Wu A. Users' guide to integrating patient-reported outcomes in electronic health records.
Baltimore: Johns Hopkins University. 2017.
55. Statista. Market share of the leading ambulatory EHR vendors in the United States as of May 2019. 2021; https://www.statista.com/statistics/1112047/us-ambulatory-ehr-vendors-top10/. Accessed February 26, 2021.
56. Francis L. Non-HIPAA Covered Entities: Data in Registries. https://ncvhs.hhs.gov/wp- content/uploads/2017/11/B2-Leslie-Francis-PCS-2017Nov28-Beyond-HIPAA-508.pdf.
57. Stevens GM, Division AL. A Brief Summary of the HIPAA Medical Privacy Rule. 2003.
58. Mulligan SP, Freeman W, Linebaugh C. Data protection law: an overview. Paper presented at: R45631. Congressional Research Service. https://crsreports. congress. gov/product/pdf2019.
59. Health UDo, Services H. Examining oversight of the privacy & security of health data collected by entities not regulated by HIPAA. *Washington, DC: US Dept of HHS.* 2016.
60. Congressional Research Service. *HIPAA, Telehealth, and COVID-19.* 2020.
61. Health UDo, Services H. Health Industry Cybersecurity Practices: Managing Threats and Protecting Patients. In.
62. Centers for Medicare & Medicaid Services. Policies and Technology for Interoperability and Burden Reduction. 2021; https://www.cms.gov/Regulations-and-Guidance/Guidance/Interoperability/index. Accessed February 18, 2021.
63. Medicare Cf, Services M. Summary of policies in the calendar year (CY) 2018 Medicare physician fee schedule (MPFS) final rule, Telehealth originating site facility fee payment amount and Telehealth services list, and CT modifier reduction list. *MLN.* 10393.
64. Medicare Cf, Services M. Frequently asked questions about billing Medicare for transitional care management services. In:2013.
65. U.S Centers for Medicare & Medicaid Services. Quality Payment

Program. 2021; https://qpp.cms.gov/mips/explore-measures?tab=improvementActivities&py=2020. Accessed February 18, 2021.
66. The National Telehealth Policy Resource Center. *State Telehealth Laws and Reimbursement Policies.* Center for Connected Health Policy;2020.
67. Day FC, Pourhomayoun M, Keeves D, et al. Feasibility study of an EHR-integrated mobile shared decision making application. *International journal of medical informatics.* 2019;124:24-30.
68. Moore SL, Fischer HH, Steele AW, et al. A mobile health infrastructure to support underserved patients with chronic disease. Paper presented at: Healthcare2014.
69. Bhavnani SP, Cohoon T, Shen C, Khedraki R, Hu S. FROM ELECTRONIC MEDICAL RECORD INTEGRATION TO REIMBURSEMENT: PRACTICAL IMPLICATIONS OF CHRONIC CARE MANAGEMENT THROUGH A REMOTE PATIENT MONITORING (CPT 99091) CARDIOVASCULAR PROGRAM. *Journal of the American College of Cardiology.* 2020;75(11_Supplement_1):3621-3621.
70. Miyamoto S, Dharmar M, Fazio S, Tang-Feldman Y, Young HM. mHealth technology and nurse health coaching to improve health in diabetes: protocol for a randomized controlled trial. *JMIR research protocols.* 2018;7(2):e45.
71. Kumar RB, Goren ND, Stark DE, Wall DP, Longhurst CA. Automated integration of continuous glucose monitor data in the electronic health record using consumer technology. *Journal of the American Medical Informatics Association.* 2016;23(3):532-537.
72. Liu M, Wronski L. Examining completion rates in web surveys via over 25,000 real-world surveys. *Social Science Computer Review.* 2018;36(1):116-124.
73. Wagner LI, Schink J, Bass M, et al. Bringing PROMIS to practice: brief and precise symptom screening in ambulatory cancer care. *Cancer.* 2015;121(6):927-934.
74. Zhang R, Burgess ER, Reddy MC, et al. Provider perspectives on the integration of patient-reported outcomes in an electronic health record. *JAMIA open.* 2019;2(1):73-80.
75. Marquard JL, Garber L, Saver B, Amster B, Kelleher M, Preusse P. Overcoming challenges integrating patient-generated data into the clinical EHR: Lessons from the CONtrolling Disease Using Inexpensive IT–Hypertension in Diabetes (CONDUIT-HID) Project. *International journal of medical informatics.* 2013;82(10):903-910.
76. Kane C. Updated data on physician practice arrangements: for the first time, fewer physicians are owners than employees. American Medical Association Policy Research Perspective [Internet]. 2019. In:2020.
77. Statcounter GlobalStats. Mobile Operating System Market Share United States Of America Jan 2020 - Jan 2021. 2021; https://gs.statcounter.com/os-market-share/mobile/united-states-of-america. Accessed February 17, 2021.
78. Shaw RJ, Bonnet JP, Modarai F, George A, Shahsahebi M. Mobile health technology for personalized primary care medicine. *Am J Med.* 2015;128(6):555-557.

79. Office of the National Coordinator for Health Information Technology. *Information Blocking and the ONC Health IT Certification Program: Extension of Compliance Dates and Timeframes in Response to the COVID-19 Public Health Emergency.* Department of Health and Human Services;2020.
80. Wosik J, Fudim M, Cameron B, et al. Telehealth transformation: COVID-19 and the rise of virtual care. *Journal of the American Medical Informatics Association.* 2020;27(6):957-962.
81. Federal Communications Commission. COVID-19 Telehealth Program. 2020; https://www.fcc.gov/covid-19-telehealth-program.
82. Federal Communications Commission. Connected Care Pilot Program. 2021; https://www.fcc.gov/wireline-competition/telecommunications-access-policy-division/connected-care- pilot-program.
83. McGrail S. Cleveland Clinic, Epic Use Remote Patient Monitoring for COVID-19. 2020; https://hitinfrastructure.com/news/cleveland-clinic-epic-use-remote-patient-monitoring-for-covid-19.
84. Siwicki B. University of Michigan Hospital deploys Epic-linked 'patient monitoring at home'. 2021; https://www.healthcareitnews.com/news/university-michigan-hospital-deploys-epic-linked-patient- monitoring-home.
85. Siwicki Bm. UPDATED: A guide to telehealth vendors in the age of COVID-19. 2020; https://www.healthcareitnews.com/news/guide-telehealth-vendors-age-covid-19. Accessed February 17, 2021.
86. Millard M. Cerner, Xealth simplify digital tool orders for telehealth, remote patient monitoring. 2020; https://www.healthcareitnews.com/news/cerner-xealth-simplify-digital-tool-orders-telehealth-remote- patient-monitoring.
87. Shaw RJ, McDuffie JR, Hendrix CC, et al. Effects of nurse-managed protocols in the outpatient management of adults with chronic conditions: a systematic review and meta-analysis. *Ann Intern Med.* 2014;161(2):113-121.
88. DeVore AD, Wosik J, Hernandez AF. The future of wearables in heart failure patients. *JACC: Heart Failure.* 2019;7(11):922-932.
89. Secrest A, Chren MM, Hopkins Z, Chen S, Ferris L, Hess R. Benefits to patient care of electronically capturing patient- reported outcomes in dermatology. *British Journal of Dermatology.* 2019;181(4):826-827.
90. Sayeed R, Gottlieb D, Mandl KD. SMART Markers: collecting patient-generated health data as a standardized property of health information technology. *NPJ digital medicine.* 2020;3(1):1-8.
91. U.S. Department of Health & Human Services. The Security Rule. 2020; https://www.hhs.gov/hipaa/for-professionals/security/index.html. Accessed February 17, 2021.
92. Rodriguez JA, Clark CR, Bates DW. Digital Health Equity as a Necessity in the 21st Century Cures Act Era. *JAMA : the journal of the American Medical Association.* 2020.
93. Federal Communications Commission. *Broadband Deployment Report: Digital Divide Narrowing Substantially.* 2019.
94. Whitacre BE, Wheeler D, Landgraf C. What can the national broadband map tell us about the health care connectivity gap? *The Journal of Rural Health.* 2017;33(3):284-289.

95. Berkowitz K, Kessler J. *The Racial Equality and Economic Opportunity Case for Expanding Broadband.* Third Way,;2019.
96. Dunn P, Hazzard E. Technology approaches to digital health literacy. *International journal of cardiology.* 2019;293:294-296.
97. The Office of the National Coordinator for Health Information Technology. *The ONC Cures Act Final Rule.* 2020.

Appendix A. Environmental Scan Search Terms

Search Strategy Report:

Topic: Shaw PGHD Oct 2020 Update

Searcher: Update by Leila Ledbetter. Original search by

Tiase et. al. Date: 10/18/2019

Table A-1. MEDLINE (via Ovid) search sets and results

Set#	Terms	Results
1 PGHD set 1	Patient Generated Health Data/	77
2 PGHD set 1	("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") adj3 (data? or dataset? or "data set?"))).ti,ab,kf,kw.	270
3 PGHD set 1	((patient* or caregiver*) adj2 (generated or recorded) adj3 (data? or dataset? or "data set?")).ti,ab,kf,kw.	1,199
4* PGHD set 1	1 OR 2 OR 3	1,246
5 PGHD set 2	(("user generated" or user-generated) adj3 (data? or "data set?" or data-set?)).ti,ab,kf,kw.	56
6 PGHD set 2	("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") adj3 (data? or dataset? or "data set?"))).ti,ab,kf,kw.	70
7 PGHD set 2	((personal* or self or patient*) adj2 data* adj2 (tracking or tracke??)).ti,ab,kf,kw.	99
8 PGHD set 2	("quantified self" or lifelog).ti,ab,kf,kw.	143
9* PGHD set 2	5 OR 6 OR 7 OR 8	332
10 PGHD set 3	Telemedicine/	24,343
11 PGHD set 3	(mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*").ti,ab,kf,kw.	25,694
12* PGHD set 3	10 OR 11	44,822
13 self care/management/ monitor	Self Report/ or ("self report*" or self-report*).ti,ab,kf,kw.	170,417

Set#	Terms	Results
14 self care/management/ monitor	self care/ or self-management/	35,567
15 self care/ management/ monitor	("self care" or "self management" or "self monitor*" or self-monitor*).ti,ab,kf,kw.	43,969
16 self care/ management/ monitor	13 OR 14 OR 15	229,662
17* self care/ management/ monitor + tech Set	16 AND (technolog* or device* or wearable*).ti,ab,kf,kw.	10,691
18 wearable devices set	Wearable Electronic Devices/	2,750
19 wearable devices set	(((body-worn or "body worn" or wearable*) adj2 (biosensor* or sensor* or device? or technolog*)) or (electronic adj1 skin)).ti,ab,kf,kw.	7,929
20* wearable devices set	18 OR 19	9,195
21 ambulatory monitoring set	Monitoring, Ambulatory/	8,196
22 ambulatory monitoring set	(monitoring adj1 (outpatient* or patient* or ambulatory)).ti,ab,kf,kw. (9088)	9,888
23* ambulatory monitoring set	21 OR 22	17,661
24 patient reported outcome set	patient reported outcome measures/	6,576
25 patient reported outcome set	("patient reported" adj4 outcome*).ti,ab,kf,kw.	22,262
26* patient reported outcome set	24 OR 25	23,943
27 all PGHD sets combined	4 OR 9 OR 12 OR 17 OR 20 OR 23 OR 26	100,463
28 EHR set 1	medical record linkage/ or medical records systems, computerized/ or health information exchange/	23,493
29 EHR set 1	((computer* or electronic or linkage) adj2 (health or medical) adj2 record?).ti,ab,kf,kw. or ehr.ti,ab.	37503
30 EHR set 1	"Meaningful Use"/ or (meaningful adj1 "use?").ti,ab,kf,kw. (1824)	1,884
31* EHR set 1	28 OR 29 OR 30	57,320
32 automat* medical records - EMR set	medical records/ or medical records, problem-oriented/	66,575
33 automat* medical records - EMR set	information systems/ or big data/ or community networks/ or geographic information systems/ or health information systems/ or knowledge bases/ or biological ontologies/ or gene ontology/ or medical informatics computing/ or public health informatics/	46,786

Set#	Terms	Results
34 automat* medical records - EMR set	database management systems/ or data systems/	7,769
35 automat* medical records - EMR set	Automation/	18,315
36 automat* medical records - EMR set	32 and (33 or 34 or 35)	1,773
37* EHR or EMR set	31 or 36	58,916
38	*Decision Support Systems, Clinical/ or (CDS or CDSS).ti,ab. or ((clinical or hospital) adj4 ("decision support system?" or "information system?")).ti,ab.	25,916
39	(("patient* portal*" or patient*) adj2 portal*).ti,ab,kf,kw.	4786
40* PGHD + EHR/EMR set	27 and 37	2770
41* PGHD + CDSS set	(27 and 38) not 40	486
42* PGHD + Patient Portal set	(27 and 39) not (40 or 41)	161
43 Final set	40 OR 41 OR 42	3417
44* Create date: August 1, 2019 to October 31, 2020	Limit 43 to dt=20190801-20201031	456

* Search term altered from term used for review by Tiase et. al.

Table A-2. Embase (embase.com) search sets and results

Set#	Terms	Results
1	'patient generated data':ti,ab,kw OR 'patient generated health data':ti,ab,kw OR 'patient-generated data':ti,ab,kw OR 'patient-generated health data':ti,ab,kw OR ((('patient generated' OR 'patient-generated') NEAR/3 (data? OR dataset? OR 'data set?')):ti,ab,kw)	258
2	((patient* OR caregiver*) NEAR/2 (generated OR recorded) NEAR/3 (data? OR dataset? OR 'data set?')):ti,ab,kw	28
3*	#1 OR #2	285
4*	(('user generated' OR 'user generated') NEAR/3 (data? OR 'data set?' OR 'data set?')):ti,ab,kw	6
5	'self recorded health data':ti,ab,kw OR 'self-recorded health data':ti,ab,kw OR ((('self-recorded' OR 'self recorded' OR 'self tracking' OR 'self tracking' OR 'self tracke??' OR 'self tracke??' OR 'self-expressed' OR 'self expressed' OR 'personally collected') NEAR/3 (data? OR dataset? OR 'data set?')):ti,ab,kw)	4
6	((personal* OR self OR patient*) NEAR/2 data* NEAR/2 (tracking OR tracke??)):ti,ab,kw	110
7	'quantified self':ti,ab,kw OR lifelog:ti,ab,kw	154

Set#	Terms	Results
8*	#5 OR #6 OR #7	263
9	'telemedicine'/exp/mj	22,281
10	mhealth:ti,ab,kw OR 'm health':ti,ab,kw OR 'mobile health':ti,ab,kw OR ehealth:ti,ab,kw OR 'e health':ti,ab,kw OR 'smart technolog*':ti,ab,kw OR smartphone*:ti,ab,kw OR 'smart phone*':ti,ab,kw OR smartwatch*:ti,ab,kw OR 'smart watch*':ti,ab,kw	32,197
11*	#9 OR #10	52,059
12	'self report'/de OR 'self report*':ti,ab,kw	239,484
13	'self care'/de	60,119
14	'self care':ti,ab,kw OR 'self management':ti,ab,kw OR 'self monitor*':ti,ab,kw	62,989
15*	#12 OR #13 OR #14	319,327
16	#15 AND (technolog*:ti,ab,kw OR device*:ti,ab,kw OR wearable*:ti,ab,kw)	14,881
17	'electronic device'/exp AND ('body worn*':ti,ab,kw OR 'body worn':ti,ab,kw OR wearable*:ti,ab,kw)	4,006
18	((('body worn' OR 'body worn' OR wearable*) NEAR/2 (biosensor* OR biometric* OR sensor* OR device? OR technolog*)):ti,ab,kw) OR ((electronic NEAR/3 skin):ti,ab,kw)	7,894
19	#16 OR #17 OR #18	24,094
20	'ambulatory monitoring'/mj	3,985
21	(monitoring NEAR/1 (outpatient* OR patient* OR ambulatory)):ti,ab,kw	14,923
22**	#20 OR #21	18,302
23	'patient-reported outcome'/de	25,079
24	('patient reported' NEAR/4 outcome*):ti,ab,kw	37,567
25	#23 OR #24	44,063
26	#3 OR #8 OR #11 OR #16 OR #19 OR #25	115,671
27	#3 OR #8 OR #11 OR #16 OR #19 OR #22 OR #25	132,256
28	'electronic health record'/de OR 'meaningful use criteria'/de OR 'electronic medical record'/de OR 'electronic patient record'/de	77,550
29	((computer* OR electronic OR linkage) NEAR/2 (health OR medical) NEAR/2 record?):ti,ab,kw	35,238
30	#28 OR #29	85,894
31	'medical record'/de	183,913
32	'information system'/de OR 'decision support system'/exp/mj OR 'hospital information system'/exp/mj OR 'medical information system'/mj OR 'nursing information system'/mj OR 'automation'/mj	85,265
33	#31 AND #32	7,899

Set#	Terms	Results
34	#30 OR #33	93,141
35	'clinical decision support system'/de	3,314
36	'clinical decision support system'/de OR cds:ti,ab OR cdss:ti,ab OR (((clinical OR hospital) NEAR/4 ('decision support system?' OR 'information system?')):ti,ab,kw)	24,090
37	#35 OR #36	24,090
38	(('patient* portal*' OR patient*) NEAR/2 portal*):ti,ab,kw	7,556
39	#27 AND #34	3,889
40	#27 AND #37 NOT #39	374
41	#27 AND #38 NOT (#39 OR #40)	243
42 Final Set	#39 OR #40 OR #41	4,506
43	#42 AND [1-8-2019]/sd NOT [1-11-2020]/sd	1,079

* Search term altered from term used for review by Tiase et. al.
** Line 22 in the original search was a duplicate. Search was adjusted accordingly.

Table A-3. CINAHL complete (Ebscohost) search sets and results

Set#	Terms	Results
1	TI (("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?")))) OR AB (("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?")))) OR TX (("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?"))))	368
2	((patient* or caregiver*) N2 (generated or recorded) N3 (data? or dataset? or "data set?"))	36,477
3*	S1 OR S2	36,715
4*	TI (("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self- tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?")))) OR AB (("self recorded health data" or "self- recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?"))))	29
5	TI (((personal* or self or patient*) N2 data* N2 (tracking or tracke??))) OR AB (((personal* or self or patient*) N2 data* N2 (tracking or tracke??)))	56
6	TI (("quantified self" or lifelog)) OR AB (("quantified self" or lifelog))	52
7	S4 OR S5 OR S6	127
8*	(MH "Telemedicine")	12,004

Set#	Terms	Results
9	TI ((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*")) OR AB ((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))	12,638
10	S8 OR S9	23,002
11*	(MH "Self Report") OR TI (("self report*" or self-report*)) OR AB (("self report*" or self-report*))	120,564
12	(MH "Self Care") OR (MH "Self-Management")	41,395
13	("self care" or "self management" or "self monitor*" or self-monitor*)	66,234
14	(S11 OR S12 OR S13)	183,624
15*	TI ((technolog* or device* or wearable*)) OR AB ((technolog* or device* or wearable*))	208,152
16	S14 AND S15	6,595
17	TI ((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin))) OR AB ((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin))) OR TX ((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin)))	5,259
18	(MH "Patient-Reported Outcomes") OR TI ("patient reported" N4 outcome*) OR AB ("patient reported" N4 outcome*)	11,830
19	S3 OR S7 OR S10 OR S16 OR S17 OR S18	80,571
20	(MH "Electronic Health Records") OR (MH "Medical Record Linkage") OR (MH "Health Information Systems") OR (MH "Clinical Information Systems") OR (MH "Patient Record Systems") OR (MH "Patient Portals") OR (MH "Electronic Data Interchange") OR (MH "Health Level 7") OR (MH "National Health Information Network")	45,696
21	TI (((computer* or electronic or linkage) N2 (health or medical) N2 record?)) OR AB (((computer* or electronic or linkage) N2 (health or medical) N2 record?))	19,768
22	(MH "Meaningful Use") OR TI (meaningful N1 "use?") OR AB (meaningful N1 "use?")	2,155
23	(MH "Medical Records") OR (MH "Problem Oriented Records")	20,415
24	(MH "Information Systems") OR (MH "Health Information Systems+") OR (MH "Management Information Systems")	62,881
25	(MH "Management Information Systems") OR (MH "Automation")	7,857
26	S23 and (S24 or S25)	1,390
27	(MH "Decision Support Systems, Clinical") OR TI ((CDS or CDSS)) OR AB ((CDS or CDSS)) OR TI (((clinical or hospital) N4 ("decision support system?" or "information system?"))) OR AB (((clinical or hospital) N4 ("decision support system?" or "information system?")))	7,838
28	TI ((("patient* portal*" or patient*) N2 portal*)) OR AB ((("patient* portal*" or patient*) N2 portal*))	1,463
29	S19 AND (S20 or S21)	3,676
30	S19 AND (S22)	93
31	S19 AND (S26)	68
32	S19 AND (S27)	545

Set#	Terms	Results
33	S19 AND (S28)	159
34	S29 OR S30 OR S31 OR S32 OR S33	4,177
35	Limiters - Published Date: 20190801-20201031	527

* Search term altered from term used for review by Tiase et. al.

Table A-4. Scopus (scopus.com) search sets and results

Set#	Terms	Results
1	((TITLE-ABS-KEY (("patient generated data" OR "patient generated health data" OR "patient-generated data" OR "patient-generated health data" OR (("patient generated" OR "patient-generated") W/3 (data? OR dataset? OR "data set?"))))) OR (TITLE-ABS-KEY ((("user generated" OR user-generated) W/3 (data? OR "data set?" OR data-set?)))) OR (TITLE- ABS-KEY (("self recorded health data" OR "self-recorded health data" OR (("self-recorded" OR "self recorded" OR "self tracking" OR self-tracking OR "self tracke??" OR self-tracke?? OR "self-expressed" OR "self expressed" OR "personally collected") W/3 (data? OR dataset? OR "data set?"))))) OR (TITLE-ABS-KEY (("quantified self" OR lifelog))) OR (TITLE-ABS-KEY (mhealth OR m-health OR "mobile health" OR ehealth OR e-health OR "smart technolog*" OR smartphone* OR "smart phone*" OR smartwatch* OR "smart watch*")) OR (TITLE-ABS-KEY (mhealth OR m-health OR "mobile health" OR ehealth OR e-health OR "smart technolog*" OR smartphone* OR "smart phone*" OR smartwatch* OR "smart watch*")) OR (TITLE-ABS-KEY ("self report*" OR self-report* OR "self care" OR "self management" OR "self monitor*" OR self- monitor*) AND TITLE-ABS-KEY (technolog* OR device* OR wearable*)) OR (TITLE-ABS-KEY ((((body-worn OR "body worn" OR wearable*) W/2 (biosensor* OR sensor* OR device? OR technolog*)) OR (electronic W/1 skin)))) OR (TITLE-ABS-KEY ("patient reported" W/4 outcome*) OR TITLE-ABS-KEY ((((body-worn OR "body worn" OR wearable*) W/2 (biosensor* OR sensor* OR device? OR technolog*)) OR (electronic W/1 skin))))) AND (TITLE-ABS-KEY (((computer* OR electronic OR linkage) W/2 (health OR medical) W/2 record?)) OR TITLE-ABS (ehr))	3,193
2	AND (ORIG-LOAD-DATE AFT 20190801 AND ORIG-LOAD-DATE BEF 20201031)	453

Table A-5. Web of Science Core Collection (Clarivate Analytics) search sets and results

Set#	Terms	Results
1	TS=("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") NEAR/3 (data? or dataset? or "data set?")))	236
2	TS=(((patient* or caregiver*) NEAR/2 (generated or recorded) NEAR/3 (data? or dataset? or "data set?")))	76
3	TS=(("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") NEAR/3 (data? or dataset? or "data set?"))))	11
4	TS=(((personal* or self or patient*) NEAR/2 data* NEAR/2 (tracking or tracke??)))	310
5	TS=((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))	73,818
6	TS=(("self report*" or self-report* or "self care" or "self management" or "self monitor*" or self-monitor*) and (technolog* or device* or wearable*))	12,940
7	TS=((((body-worn or "body worn" or wearable*) NEAR/2 (biosensor* or sensor* or device? or technolog*)) or (electronic NEAR/1 skin)))	22,592
8	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7	104,713
9	TS=(((computer* or electronic or linkage) NEAR/2 (health or medical) NEAR/2 record?))	23,532
10	TS=((meaningful NEAR/1 "use?"))	281
11	TS=(((clinical or hospital) NEAR/4 ("decision support system?" or "information system?")))	4,792
12	#10 OR #11	5,073
13	#9 AND #8	997
14	#10 AND #8	6
15	#12 AND #8	216
16	TS=(("patient* portal*" or patient*) NEAR/2 portal*)	5,648
17	#16 AND #8	265
18	#17 OR #15 OR #14 OR #13	1,367
19	#18 AND Timespan=2019-2020	336

Note - Topic changed from review by Tiase et. al. to TS.

Table A-6. Academic Search Complete (Ebscohost) search sets and results

Set#	Terms	Results
1	TI ((("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?"))))) OR AB ((("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?"))))) OR KW ((("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?")))))	90
2	TI (((patient* or caregiver*) N2 (generated or recorded) N3 (data? or dataset? or "data set?"))) OR AB (((patient* or caregiver*) N2 (generated or recorded) N3 (data? or dataset? or "data set?"))) OR KW (((patient* or caregiver*) N2 (generated or recorded) N3 (data? or dataset? or "data set?")))	1,137
3	(S1 OR S2)	1,137
4	TI ((("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?"))))) OR AB ((("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?"))))) OR KW ((("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?")))))	49
5	TI ((((personal* or self or patient*) N2 data* N2 (tracking or tracke??)))) OR AB ((((personal* or self or patient*) N2 data* N2 (tracking or tracke??)))) OR KW ((((personal* or self or patient*) N2 data* N2 (tracking or tracke??))))	101
6	TI ((("quantified self" or lifelog))) OR AB ((("quantified self" or lifelog))) OR KW ((("quantified self" or lifelog)))	216
7	DE "TELEMEDICINE"	13,436
8	TI (((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))) OR AB (((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))) OR KW (((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*")))	39,570
9	(DE "HEALTH self-care") OR (DE "PATIENT self-monitoring")	12,596
10	TI ((technolog* or device* or wearable*)) OR AB ((technolog* or device* or wearable*)) OR KW ((technolog* or device* or wearable*))	1,689,432
11	S9 AND S10	813

Set#	Terms	Results
12	TI (((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin)))) OR AB (((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin)))) OR KW (((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin))))	7,823
13	TI ("patient reported" N4 outcome*) OR AB ("patient reported" N4 outcome*) OR KW ("patient reported" N4 outcome*)	12,581
14	S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S11 OR S12 OR S13	72,042
15	DE "ELECTRONIC health records"	14,192
16	TI ((((computer* or electronic or linkage) N2 (health or medical) N2 record?))) OR AB ((((computer* or electronic or linkage) N2 (health or medical) N2 record?))) OR KW ((((computer* or electronic or linkage) N2 (health or medical) N2 record?)))	20,649
17	S15 OR S16	25,172
18	TI (meaningful N1 "use?") OR AB (meaningful N1 "use?") OR KW (meaningful N1 "use?")	1,010
19	TI ((((clinical or hospital) N4 ("decision support system?" or "information system?"))) OR AB ((((clinical or hospital) N4 ("decision support system?" or "information system?"))) OR KW ((((clinical or hospital) N4 ("decision support system?" or "information system?")))	1,954
20	TI (((("patient* portal*" or patient*) N2 portal*))) OR AB (((("patient* portal*" or patient*) N2 portal*))) OR KW (((("patient* portal*" or patient*) N2 portal*)))	2,037
21	S14 AND S17	1,522
22	S14 AND S18	18
23	S14 AND S19	91
24	S14 AND S20	106
25	S21 OR S22 OR S23 OR S24	1,668
26	Limiters - Published Date: 20190801-20201031	213

Note: Previous search by Tiase et. al. was conducted in Academic Search Ultimate (Ebscohost).

Table A-7. Dissertations & Theses Global (ProQuest) search sets and results

Set#	Terms	Results
1	noft(("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") NEAR/3 (data? or dataset? or "data set?")))) OR noft(((patient* or caregiver*) NEAR/2 (generated or recorded) NEAR/3 (data? or dataset? or "data set?")))	110
2	noft((((patient* or caregiver*) NEAR/2 (generated or recorded) NEAR/3 (data? or dataset? or "data set?"))))	110
3	S1 OR S2	110
4	noft(("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") NEAR/3 (data? or dataset? or "data set?"))))	24
5	noft(((personal* or self or patient*) NEAR/2 data* NEAR/2 (tracking or tracke??)))	17
6	noft("quantified self" or lifelog)	49
7	noft(telemedicine or mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or"smart watch*")	5,423
8	noft(("Self care" OR "self report*" OR "Self monitor*") NEAR/5 (technolog* or device* or wearable*))	263
9	noft((((body-worn or "body worn" or wearable*) NEAR/2 (biosensor* or sensor* or device? or technolog*)) or (electronic NEAR/1 skin)) ("Self care" OR "self report*" OR "Self monitor*") NEAR/5 (technolog* OR device* OR wearable*))	8
10	noft(("patient reported" NEAR/4 outcome*))	428
11	S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10	6,251
12	noft(((computer* or electronic or linkage) NEAR/2 (health or medical) NEAR/2 record?))	2,602
13	noft((meaningful NEAR/1 "use?"))	431
14	noft(((clinical or hospital) NEAR/4 ("decision support system?" or "information system?")))	696
15	noft((("patient* portal*" or patient*) NEAR/2 portal*))	158
16	S11 and S12	116
17	S11 and S13	7
18	S11 and S14	23
19	S11 and S15	16
20	S16 or S17 or S18 or S19	149
21	Date filter: 2019-08-01 - 2020-10-31	10

IEEE Xplore Digital Library (ieee.org)

1) "patient generated" OR patient-generated

   Filters Applied: medical information systems, electronic health

   records Dates: 2019-2020

   3 results

2) (("patient generated" OR patient-generated)) AND (electronic health record*) 0 results
3) (("user generated" OR user-generated)) AND (electronic health record*) 0 results

Inspec (engineeringvillage.com, Elsevier)

9 records found in Inspec for 2019-2021:

(((("patient generated" or patient-generated or "patient reported" or patient-reported or "user generated" or user-generated or "user reported" or user-reported) AND electronic health record*)) WN ALL)

Appendix B. Search Strategies by Database

Search Strategies by Database (Tiase et. al.)

Ovid MEDLINE(R) August 2, 2019

1 Patient Generated Health Data/ (38)
2 ("patient generated data" or "patient generated health data" or "patient-generated data" or "patient- generated health data" or (("patient generated" or "patient-generated") adj3 (data? or dataset? or "data set?"))).ti,ab,kf,kw. (188)
3 ((patient* or caregiver*) adj2 (generated or recorded) adj3 (data? or dataset? or "data set?")).ti,ab,kf,kw. (1007)
4 or/1-3 [PGHD set1] (1035)
5 (("user generated" or user-generated) adj3 (data? or "data set?" or data-set?)).ti,ab,kf,kw. (45)
6 ("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") adj3 (data? or dataset? or "data set?"))).ti,ab,kf,kw. (58)
7 ((personal* or self or patient*) adj2 data* adj2 (tracking or tracke??)).ti,ab,kf,kw. (82)
8 ("quantified self" or lifelog).ti,ab,kf,kw. (122)
9 or/5-8 [PGHD set 2] (280)
10 Telemedicine/ (19941)
11 (mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*").ti,ab,kf,kw. (19156)
12 or/10-11 [mhealth. PGHD set 3] (35286)
13 Self Report/ or ("self report*" or self-report*).ti,ab,kf,kw. (152026)
14 self care/ or self-management/ (32935)
15 ("self care" or "self management" or "self monitor*" or self-monitor*).ti,ab,kf,kw. (38860)
16 or/13-15 [self care/management/monitor] (205737)
17 16 and (technolog* or device* or wearable*).ti,ab,kf,kw. [self care/mgt/monitor + tech Set] (9011)
18 Wearable Electronic Devices/ (1217)
19 (((body-worn or "body worn" or wearable*) adj2 (biosensor* or sensor* or device? or technolog*)) or (electronic adj1 skin)).ti,ab,kf,kw. (5464)
20 or/18-19 [wearable devices set] (6002)
21 Monitoring, Ambulatory/ (7778)
22 (monitoring adj1 (outpatient* or patient* or ambulatory)).ti,ab,kf,kw. (9088)
23 or/21-22 [ambulatory monitoring set] (16479)
24 patient reported outcome measures/ (3549)
25 ("patient reported" adj4 outcome*).ti,ab,kf,kw. (16952)
26 or/24-25 [patient reported outcome set] (17809)
27 or/4,9,12,17,20,23,26 [all PGHD sets combined] (80242)
28 medical record linkage/ or medical records systems, computerized/ or health

information exchange/ (23092)
29 ((computer* or electronic or linkage) adj2 (health or medical) adj2 record?).ti,ab,kf,kw. or ehr.ti,ab. (30532)
30 "Meaningful Use"/ or (meaningful adj1 "use?").ti,ab,kf,kw. (1824) 31 or/28-30 [EHR set 1] (50039)
32 medical records/ or medical records, problem-oriented/ (65892)

33 information systems/ or big data/ or community networks/ or geographic information systems/ or health information systems/ or knowledge bases/ or biological ontologies/ or gene ontology/ or medical informatics computing/ or public health informatics/ (42946)
34 database management systems/ or data systems/ (7635)
35 Automation/ (17263)
36 32 and (or/33-35) [automat* medical records - EMR set] (1758) 37 or/31,36 [EHR or EMR set] (51622)
38 *Decision Support Systems, Clinical/ or (CDS or CDSS).ti,ab. or ((clinical or hospital) adj4 ("decision support system?" or "information system?")).ti,ab. (23093)
39 (("patient* portal*" or patient*) adj2 portal*).ti,ab,kf,kw. (4401)
40 and/27,37 [PGHD + EHR/EMR set] (2342) 41 (and/27,38) not 40 [PGHD + CDSS set] (424)
42 (and/27,39) not (40 or 41) [PGHD + Patient Portal set] (118) 43 or/40-42 [Final Set] (2884)
44 remove duplicates from 43 (2878)

Embase (embase.com) August 9, 2019

#43 #40 OR #41 OR #42 3593

#42 #28 AND #39 NOT (#40 OR #41) 175

#41 #28 AND #38 NOT #40 299

#40 #28 AND #35 3119

#39 (('patient* portal*' OR patient*) NEAR/2

portal*):ti,ab,kw 6551 #38 #36 OR #37 20466

#37 'clinical decision support system'/de OR cds:ti,ab OR cdss:ti,ab OR (((clinical OR hospital) NEAR/4 ('decision support system?' OR 'information

system?')):ti,ab,kw) 20466 #36 'clinical decision support system'/de

2365

#35 #31 OR #34 78122

#34 #32 AND #33 7853

#33 'information system'/de OR 'decision support system'/exp/mj OR 'hospital information system'/exp/mj OR 'medical information system'/mj OR 'nursing information system'/mj OR 'automation'/mj 80653

#32 'medical record'/de 171140

#31 #29 OR #30 236339

#30 ((computer* OR electronic OR linkage) NEAR/2 (health OR medical) NEAR/2 record?):ti,ab,kw 28527

#29 'electronic health record'/de OR 'meaningful use criteria'/de OR 'electronic medical record'/de OR 'electronic patient record'/de 63978

#28 #3 OR #8 OR #11 OR #16 OR #19 OR #23 OR #26 105463
#27 #3 OR #8 OR #11 OR #16 OR #19 OR #26 89781

#26 #24 OR #25 33477

#25 ('patient reported' NEAR/4 outcome*):ti,ab,kw 29160

#24 'patient-reported outcome'/de 16356

#23 #20 OR #21 OR #22 17182

#22 (monitoring NEAR/1 (outpatient* OR patient* OR

ambulatory)):ti,ab,kw 13838 #21 (monitoring NEAR/1 (outpatient* OR

patient* OR ambulatory)):ti,ab,kw 13838 #20 'ambulatory monitoring'/mj

3930

#19 #16 OR #17 OR #18 18663

#18 ((('body worn' OR 'body worn' OR wearable*) NEAR/2 (biosensor* OR biometric* OR sensor* OR device? OR technolog*)):ti,ab,kw) OR ((electronic NEAR/3 skin):ti,ab,kw) 5311

#17 'electronic device'/exp AND ('body worn*':ti,ab,kw OR 'body worn':ti,ab,kw OR wearable*:ti,ab,kw) 2485

#16 #15 AND (technolog*:ti,ab,kw OR device*:ti,ab,kw OR wearable*:ti,ab,kw) 12539

#15 #12 OR #13 OR #14 286030

#14 'self care':ti,ab,kw OR 'self management':ti,ab,kw OR 'self

monitor*':ti,ab,kw 55772 #13 'self care'/de 53739

#12 'self report'/de OR 'self

report*':ti,ab,kw 214338 #11 #9 OR #10

40921

#10 mhealth:ti,ab,kw OR 'm health':ti,ab,kw OR 'mobile health':ti,ab,kw OR ehealth:ti,ab,kw OR 'e health':ti,ab,kw OR 'smart technolog*':ti,ab,kw OR smartphone*:ti,ab,kw OR 'smart phone*':ti,ab,kw OR smartwatch*:ti,ab,kw OR 'smart watch*':ti,ab,kw 24142

#9 'telemedicine'/exp/mj 18599

#8 #5 OR #6 OR #7 211

#7 'quantified self':ti,ab,kw OR lifelog:ti,ab,kw 120

#6 ((personal* OR self OR patient*) NEAR/2 data* NEAR/2 (tracking OR

tracke??)):ti,ab,kw 92 #5 'self recorded health data':ti,ab,kw OR 'self-recorded health

data':ti,ab,kw OR ((('self-recorded' OR 'self recorded' OR 'self tracking' OR 'self tracking' OR 'self tracke??' OR 'self tracke??' OR 'self- expressed' OR 'self expressed' OR 'personally collected') NEAR/3 (data? OR dataset? OR 'data set?')):ti,ab,kw) 2

#4 (('user generated' OR 'user generated') NEAR/3 (data? OR 'data set?' OR 'data

set?')):ti,ab,kw 6 #3#1 OR #2 188

#2 ((patient* OR caregiver*) NEAR/2 (generated OR recorded) NEAR/3 (data? OR dataset? OR 'data set?')):ti,ab,kw 19

#1 'patient generated data':ti,ab,kw OR 'patient generated health data':ti,ab,kw OR 'patient-generated data':ti,ab,kw OR 'patient-generated health data':ti,ab,kw OR ((('patient generated' OR 'patient-generated') NEAR/3 (data? OR dataset? OR 'data set?')):ti,ab,kw) 169

CINAHL Complete (Ebscohost) August 19, 2019

S34 S29 OR S30 OR S31 OR S32 OR S33 3,288

S33 S19 AND (S28) 118

S32 S19 AND (S27) 439

S31 S19 AND (S26) 57

S30 S19 AND (S22) 58

S29 S19 AND (S20 or S21) 2,894

S28 TI ((("patient* portal*" or patient*) N2 portal*)) OR AB ((("patient* portal*" or patient*) N2 portal*)) 1,114

S27 (MH "Decision Support Systems, Clinical") OR TI ((CDS or CDSS)) OR AB ((CDS or CDSS)) OR TI (((clinical or hospital) N4 ("decision support system?" or "information system?"))) OR AB (((clinical or hospital) N4 ("decision support system?" or "information system?"))) 6,443

S26 S23 and (S24 or S25) 1,217

S25 (MH "Management Information Systems") OR (MH "Automation") 6,930

S24 (MH "Information Systems") OR (MH "Health Information Systems+") OR (MH "Management Information Systems") 54,457

S23 (MH "Medical Records") OR (MH "Problem Oriented Records") 18,351

S22 (MH "Meaningful Use") OR TI (meaningful N1 "use?") OR AB

(meaningful N1 "use?")
1,619

S21 TI (((computer* or electronic or linkage) N2 (health or medical) N2 record?)) OR AB (((computer* or electronic or linkage) N2 (health or medical) N2 record?)) 14,551

S20 (MH "Electronic Health Records") OR (MH "Medical Record Linkage") OR (MH "Health Information Systems") OR (MH "Clinical Information Systems") OR (MH "Patient Record Systems") OR (MH "Patient Portals") OR (MH "Electronic Data Interchange") OR (MH "Health Level 7") OR (MH "National Health Information Network") 38,831

S19 S3 OR S7 OR S10 OR S16 OR S17 OR S18 63,951

S18 (MH "Patient-Reported Outcomes") OR TI ("patient reported" N4 outcome*) OR AB ("patient reported" N4 outcome*) 8,857

S17 TI ((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin))) OR AB ((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin))) OR TX ((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin))
) 3,856

S16 S14 AND S15 5,289

S15 TI ((technolog* or device* or wearable*)) OR AB ((technolog* or device* or wearable*)) 170,718

S14 (S11 OR S12 OR S13) 155,191

S13 ("self care" or "self management" or "self monitor*" or self-monitor*) 52,763

S12 (MH "Self Care") OR (MH "Self-Management") 34,811

S11 (MH "Self Report") OR TI (("self report*" or self-report*)) OR AB (("self report*" or self- report*)) 105,081

S10 S8 OR S9 17,592

S9 TI ((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*")) OR AB ((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))9,339

S8 (MH "Telemedicine") 9,398

S7 S4 OR S5 OR S6 104

S6 TI (("quantified self" or lifelog)) OR AB (("quantified self" or lifelog)) 42

S5 TI (((personal* or self or patient*) N2 data* N2 (tracking or tracke??))) OR AB (((personal* or self or patient*) N2 data* N2 (tracking or tracke??))) 46

S4 TI (("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?")))) OR AB (("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self- tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?")))) 25

S3 S1 OR S2 30,360

S2 ((patient* or caregiver*) N2 (generated or recorded) N3 (data? or dataset? or "data set?")) 30,173

S1 TI (("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?")))) OR AB (("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?")))) OR TX (("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?")))) 266

Scopus (scopus.com) August 19, 2019

((TITLE-ABS-KEY (("patient generated data" OR "patient generated health data" OR "patient- generated data" OR "patient-generated health data" OR (("patient generated" OR "patient-generated"
) W/3 (data? OR dataset? OR "data set?"))))) OR (TITLE-ABS-KEY ((("user generated" OR user-generated) W/3 (data? OR "data set?" OR data-set?)))) OR (TITLE-ABS-KEY (("self recorded health data" OR "self-recorded health data" OR (("self-recorded" OR "self recorded" OR "self tracking" OR self-tracking OR "self tracke??" OR self-tracke?? OR "self-expressed" OR "self expressed" OR "personally collected") W/3 (data? OR dataset? OR "data set?"))))) OR (TITLE-ABS-KEY (("quantified self" OR lifelog))) OR (TITLE-ABS-KEY (mhealth OR m- health OR "mobile health" OR ehealth OR e-health OR "smart technolog*" OR smartphone* OR "smart phone*" OR smartwatch* OR "smart watch*")) OR (TITLE-ABS-KEY (mhealth OR m- health OR "mobile health" OR ehealth OR e-health OR "smart technolog*" OR smartphone* OR "smart phone*" OR smartwatch* OR "smart watch*")) OR (TITLE-ABS-KEY ("self report*" OR self-report* OR "self care" OR "self management" OR "self monitor*" OR self-monitor*) AND TITLE-ABS-KEY (technolog* OR device* OR wearable*)) OR (TITLE-ABS-KEY ((((body- worn OR "body worn" OR wearable*) W/2 (biosensor* OR sensor* OR device? OR technolog*
)) OR (electronic W/1 skin)))) OR (TITLE-ABS-KEY ("patient reported" W/4 outcome*) OR TITLE-ABS-KEY ((((body-worn OR "body worn" OR wearable*) W/2 (

biosensor* OR sensor* OR device? OR technolog*)) OR (electronic W/1 skin)))))
AND (TITLE-ABS-KEY (((computer* OR electronic OR linkage) W/2 (health OR medical) W/2 record?)) OR TITLE- ABS (ehr))

2,647 document results

Web of Science Core Collection (Clarivate Analytics) August 19, 2019

18 761 #17 OR #15 OR #14 OR #13

17 182 #16 AND #8

16 4,997 TS= (("patient* portal*" or patient*) NEAR/2 portal*)

15 123 #12 AND #8

14 4 #10 AND #8

13 526 #9 AND #8

12 3,197 #10 OR #11

11 3,028 TOPIC: (((clinical or hospital) NEAR/4 ("decision support system?" or "information system?")))

10 169 TOPIC: ((meaningful NEAR/1 "use?"))

9 16,574 TS=(((computer* or electronic or linkage) NEAR/2 (health or medical) NEAR/2 record?))

8 49,164 #7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1

7 9,922 TOPIC: ((((body-worn or "body worn" or wearable*) NEAR/2 (biosensor* or sensor* or device? or technolog*)) or (electronic NEAR/1 skin)))

6 9,320 TOPIC: (("self report*" or self-report* or "self care" or "self management" or "self monitor*" or self-monitor*) and (technolog* or device* or wearable*))

5 32,138 TOPIC: ((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))

4 194 TOPIC: (((personal* or self or patient*) NEAR/2 data* NEAR/2 (tracking or tracke??)))

3 7 TOPIC: (("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") NEAR/3 (data? or dataset? or "data set?"))))

2 61 TOPIC: (((patient* or caregiver*) NEAR/2 (generated or recorded) NEAR/3 (data? or dataset? or "data set?")))

1 124 TS=("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-

generated") NEAR/3 (data? or dataset? or "data set?")))

Academic Search Ultimate (Ebscohost) August 19, 2019

S25 S21 OR S22 OR S23 OR S24 1,403

S24 S14 AND S20 81

S23 S14 AND S19 81

S22 S14 AND S18 12

S21 S14 AND S17 1,279

S20 TI (((("patient* portal*" or patient*) N2 portal*))) OR AB (((("patient* portal*" or patient*) N2 portal*))) OR KW (((("patient* portal*" or patient*) N2 portal*))) 1,764

S19 TI ((((clinical or hospital) N4 ("decision support system?" or "information system?"))) OR AB((((clinical or hospital) N4 ("decision support system?" or "information system?"))) OR KW ((((clinical or hospital) N4 ("decision support system?" or "information system?"))) 1,607

S18 TI (meaningful N1 "use?") OR AB (meaningful N1 "use?") OR KW (meaningful N1 "use?") 864

S17 S15 OR S16 20,394

S16 TI ((((computer* or electronic or linkage) N2 (health or medical) N2 record?))) OR AB ((((computer* or electronic or linkage) N2 (health or medical) N2 record?))) OR KW ((((computer* or electronic or linkage) N2 (health or medical) N2 record?))) 16,452

S15 DE "ELECTRONIC health records" 11,101

S14 S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S11 OR S12 OR S13 60,198

S13 TI ("patient reported" N4 outcome*) OR AB ("patient reported" N4 outcome*) OR KW ("patient reported" N4 outcome*) 9,713

S12 TI (((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin)))) OR AB (((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin)))) OR KW (((((body-worn or "body worn" or wearable*) N2 (biosensor* or sensor* or device? or technolog*)) or (electronic N1 skin)))) 5,655

S11 S9 AND S10 720

S10 TI ((technolog* or device* or wearable*)) OR AB ((technolog* or device* or wearable*)) OR KW ((technolog* or device* or wearable*)) 1,547,951

S9 (DE "HEALTH self-care") OR (DE "PATIENT self-monitoring") 11,478

S8 TI (((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))) OR AB (((mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))) OR KW (((mHealth or m-health or "mobile health" or ehealth or e- health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*"))) 34,767

S7 DE "TELEMEDICINE" 10,945

S6 TI((("quantified self" or lifelog))) OR AB ((("quantified self" or lifelog))) OR KW ((("quantified self" or lifelog))) 183

S5 TI ((((personal* or self or patient*) N2 data* N2 (tracking or tracke??)))) OR AB ((((personal* or self or patient*) N2 data* N2 (tracking or tracke??)))) OR KW ((((personal* or self or patient*) N2 data* N2 (tracking or tracke??)))) 77

S4 TI ((("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?"))))) OR AB ((("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self- tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?"))))) OR KW ((("self recorded health data" or "self- recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") N3 (data? or dataset? or "data set?"))))) 36

S3 (S1 OR S2) 932

S2 TI (((patient* or caregiver*) N2 (generated or recorded) N3 (data? or dataset? or "data set?"))) OR AB (((patient* or caregiver*) N2 (generated or recorded) N3 (data? or dataset? or "data set?"))) OR KW (((patient* or caregiver*) N2 (generated or recorded) N3 (data? or dataset? or "data set?"))) 932

S1 TI ((("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?"))))) OR AB ((("patient generated data" or "patient generated health data" or "patient- generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") N3 (data? or dataset? or "data set?"))))) OR KW ((("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient- generated") N3 (data? or dataset? or "data set?"))))) 51

Dissertations & Theses Global (ProQuest)August 19, 2019

S20 S16 or S17 or S18 or S19 123

S19 S11 and S15 10

S18 S11 and S14 23

S17 S11 and S13 7

S16 S11 and S12 93

S15 noft((("patient* portal*" or patient*) NEAR/2 portal*)) 135

S14 noft(((clinical or hospital) NEAR/4 ("decision support system?" or "information system?"))) 650

S13 noft((meaningful NEAR/1 "use?")) 406

S12 noft(((computer* or electronic or linkage) NEAR/2 (health or medical) NEAR/2

record?) 2,157 S11 S3 or S4 or S5 or S6 or S7 or S8

or S9 or S10 5,232

S10 noft(("patient reported" NEAR/4 outcome*)) 342

S9 noft((((body-worn or "body worn" or wearable*) NEAR/2 (biosensor* or sensor* or device? or technolog*)) or (electronic NEAR/1 skin)) ("Self care" OR "self report*" OR "Self monitor*") NEAR/5 (technolog* OR device* OR wearable*)) 9

S8 noft(("Self care" OR "self report*" OR "Self monitor*") NEAR/5 (technolog* or device* or wearable*)) 243

S7 noft(telemedicine or mHealth or m-health or "mobile health" or ehealth or e-health or "smart technolog*" or smartphone* or "smart phone*" or smartwatch* or "smart watch*") 4,529

S6 noft("quantified self" or lifelog) 43

S5 noft(((personal* or self or patient*) NEAR/2 data* NEAR/2 (tracking or tracke??))) 11

S4 noft(("self recorded health data" or "self-recorded health data" or (("self-recorded" or "self recorded" or "self tracking" or self-tracking or "self tracke??" or self-tracke?? or "self-expressed" or "self expressed" or "personally collected") NEAR/3 (data? or dataset? or "data set?")))) 19

Select item 3

S3 S1 OR S2 91

S2 noft((((patient* or caregiver*) NEAR/2 (generated or recorded) NEAR/3 (data? or dataset? or "data set?")))) 91

S1 noft(("patient generated data" or "patient generated health data" or "patient-generated data" or "patient-generated health data" or (("patient generated" or "patient-generated") NEAR/3 (data? or dataset? or "data set?")))) OR noft(((patient* or caregiver*) NEAR/2 (generated or recorded) NEAR/3 (data? or dataset? or "data set?"))) 91

IEEE Xplore Digital Library (ieee.org) August 19, 2019

1) "patient generated" OR patient-generated
   Filters Applied: medical information systems, electronic

health records 7 results

2) (("patient generated" OR patient-generated)) AND (electronic health record*) 7 results
3) (("user generated" OR user-generated)) AND (electronic health record*) 3 results

Inspec (engineeringvillage.com, Elsevier) August 19, 2019

39 records found in Inspec for 1884-2020:

((("patient generated" or patient-generated or "patient reported" or patient-reported or "user generated" or user-generated or "user reported" or user-reported) AND electronic health record*) WN ALL)

Appendix C. EHR Vendor Survey

EHR Vendor Questionnaire

Q1 What is the name of the EHR company you represent?

We will not associate these answers with you or your company.

Q2 Does your EHR allow for PGHD to be ingested?
Yes No (if no skip to question X)

Q3 How long has your EHR allowed for PGHD to be ingested? ______

Q4 Do you allow for a Bring Your Own Device (BYOD) model?
Yes No

Q5 To process and manage PGHD does your EHR require custom built functionality or does pre-built functionality exist, or both?

Custom built functionality is needed

Pre-built functionality exists
Both

Q6 Is PGHD inclusion part of the original contract with clients or an add-on? (select all that apply)
Original Contract
Add-on

Q7 Can PGHD be received outside of the patient portal?
Yes No Not Sure

Q8 Is PGHD accessible by providers/health system to intervene?
Yes No

Q9 Does your EHR have functionality to notify providers regarding PGHD (i.e., exists, needs action or is out of range)? (one selection please)
Yes - please let us know how they are to be notified in the text box below: ____________
No

Q10 Similarly, does your EHR have functionality to notify patients regarding PGHD?
Yes - are notifications sent to patients about abnormal PGHD or the need to upload data from mobile health devices or patient-reported outcome surveys? ___________
No
Not sure

Q11 Does your EHR have the capability to send patient data from the EHR to mobile health apps?
Yes - Please let us know below, if this data is also available in graphical form: __________
No
Not sure

Q12 What type of PGHD already are or will potentially be integrated? (select all that apply)

Blood pressure	Heart rate	SpO2 – Oxygen monitoring
Respirations	Weight	Temperature
Glucose	Rhythm strips	Actigraphy
Steps	Jogging/running/biking distance	Fluid intake Sleep cycles
Menstrual cycles	Health history	Treatment history
Symptoms	Smoking	Diet/nutrition

Questionnaires/Assessment/PRO/PROM responses including: (select all that apply)

Satisfaction	Review of symptoms
Quality of life	Mental health (mood/motivation)

Patient health questionnaires: (select all that apply)
Screening, Brief Intervention and Referral to Treatment (SBIRT)
Social determinants of health
COVID symptoms

Other - Please provide more information about what your EHR can potentially be or already is Integrated which is not listed above: __________

Q13 Does your EHR allow for the push/active or pull/passive transfer of PGHD? (select all that apply)

Push/active Pull/passive

Q14 What technical approach to PGHD integration does your EHR Support (select all that apply):

HL7	FHIR	Standardized APIs
Custom APIs	Web services	Other _________
PDF	Don't know	

Q15 Does your EHR use design schemas such as Open mHealth? (OmH; IEEE P1752 standards process)?

Yes No Not sure

Q16 What standardized medical coding terms are leveraged for PGHD by users of your EHR?

SNOMED	LOINC	RxNorm
CPT	ICD-9 or ICD-10	MedDRA
FDA	HL7	NDC
RadLex	DICOM	UCUM
IEEE	SPL	Other not listed: _____
Not sure	None	

Q17 What platforms does your EHR partner with to integrate PGHD?

Apple HealthKit	Google Fit	Other:__________
None	Not sure	

Q18 How many tools, products and 3rd party companies integrate PGHD into your EHR?

0 1-5 5-10 10-20 20+

Q19 Which tools, products and 3rd party companies integrate PGHD into your EHR?

Fitbit	Garmin	Apple Watch	Livongo	AliveCor
TytoCare	Withings	iHealth	Countour	Omron
Dexcom	Quardio	Glooko	Welch-Allen	Other:_______

Q20 Does your EHR have the ability to translate PGHD in different languages?

No Yes - what languages (i.e., Spanish): ________ Not sure

Q21 Does your EHR have the ability to consume PGHD in different languages?

No Yes - what languages (i.e., Spanish): ________ Not sure

Q22 Are their readily available resources through your patient portal for patients about PGHD?

Yes - what kind of resources?__________ No Not sure

Q23 Do patients have the ability to:

Easily connect to supported devices without practice assistance or tech support
Require a clinic to activate prescribed devices
Not sure

Q24 Follow-up We would like to have a 30-minute follow-up to these questions. Is there someone or a group we could speak with to dive deeper?

Yes - We would appreciate it if you would let us know whom to contact and how we might reach them: ____________
No

Q25 Are there any organizations that you work with that you feel are leaders in PGHD use we could reach out to? If so, please provide your reference and contact information:

Yes:________ No

Q26 If you would provide your contact information, we would be glad to send you a copy of our Environmental Scan and Guide when it is finalized:

First Name:________Last Name: ___________
Email Address:________ Phone Number:________

Appendix D. EHR Vendor Interview Guide

Follow-up EHR Vendor Interview Question Guide

Client:
Date:
Recording:

1. What common factors contribute to the success of making integration of PGHD actionable?

2. What common factors contribute to the challenges of making PGHD integration actionable?

3. What resources are needed for health systems or ambulatory care clinics to incorporate PGHD?

4. If you as a vendor are involved in the build of integrating PGHD into the EHR, what is your role and how long does it typically take?

5. If PGHD is an add-on, what % of clients buy it? Do you have a feel for how many clients use it?

6. Who bears the cost of API development – the vendor or the customer? Probe: What do you expect the customer to do vs. not do?

7. For partner platforms (e.g., Validic, Xealth, Google Fit, etc.) is that the health system or EHR vendor's responsibility for development and cost?

8. What security provisions are made to protect the patient if the patient's device is lost?

9. What security provisions are made to protect your system?

10. How do you approach privacy with PGHD given that data is outside of HIPAA until it is shared with the health system?
    Probe: Is there a model or framework you use?

Appendix E. Excluded Articles

Table E-1. Excluded articles

Authors	Title	Year	Journal	Exclusion Reason
Aberger, E. W.; Migliozzi, D.; Follick, M. J.; Malick, T.; Ahern, D. K.	Enhancing patient engagement and blood pressure management for renal transplant recipients via home electronic monitoring and web-enabled collaborative care	2014	Telemedicine Journal and e-Health	Non-EHR integration
Abernethy, A. P.; Ahmad, A.; Zafar, S. Y.; Wheeler, J. L.; Reese, J. B.; Lyerly, H. K.	Electronic patient-reported data capture as a foundation of rapid learning cancer care	2010	Medical Care	Non-EHR integration
Abernethy, A. P.; Wheeler, J. L.; Zafar, S. Y.	Management of gastrointestinal symptoms in advanced cancer patients: the rapid learning cancer clinic model	2010	Current Opinion in Supportive & Palliative Care	Non-EHR integration
Absolom, K.; Gibson, A.; Velikova, G.	Engaging Patients and Clinicians in Online Reporting of Adverse Effects During Chemotherapy for Cancer The eRAPID System (Electronic Patient Self-Reporting of Adverse Events: Patient Information and aDvice)	2019	Medical Care	Inpatient setting
Absolom, K.; Gibson, A.; Velikova, G.	Engaging Patients and Clinicians in Online Reporting of Adverse Effects During Chemotherapy for Cancer: The eRAPID System (Electronic Patient Self-Reporting of Adverse Events: Patient Information and aDvice)	2019	Medical Care	Duplicate
Absolom, K.; Holch, P.; Warrington, L.; Samy, F.; Hulme, C.; Hewison, J.; Morris, C.; Bamforth, L.; Conner, M.; Brown, J.; Velikova, G.; e, Rapid systemic treatment work group	Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice (eRAPID): a randomised controlled trial in systemic cancer treatment	2017	BMC Cancer	Wrong study design
Adams, W. G.; Fuhlbrigge, A. L.; Miller, C. W.; Panek, C. G.; Gi, Y.; Loane, K. C.; Madden, N. E.; Plunkett, A. M.; Friedman, R. H.	TLC-Asthma: an integrated information system for patient-centered monitoring, case management, and point-of-care decision support	2003	AMIA ... Annual Symposium Proceedings/AMIA Symposium	Insufficient data
Adler-Milstein, J.; Nong, P.	Early experiences with patient generated health data: Health system and patient perspectives	2019	Journal of the American Medical Informatics Association	Wrong outcomes
Ahanathapillai, V.; Amor, J. D.; James, C. J.	Assistive technology to monitor activity, health and wellbeing in old age: The wrist wearable unit in the USEFIL project	2015	Technology and Disability	Non-EHR integration
Ahmad, Fahd A.; Payne, Philip R. O.; Lackey, Ian; Komeshak, Rachel; Kenney, Kenneth; Magnusen, Brianna; Metts, Christopher; Bailey, Thomas	Using REDCap and Apple ResearchKit to integrate patient questionnaires and clinical decision support into the electronic health record to improve sexually transmitted infection testing in the emergency department	2020	Journal of the American Medical Informatics Association	Not Patient Generated Health Data
Ala'Aldeen, K.; Stones, N.; Woolf, D.; Bayman, N.; Coote, J.; Harris, M.; Pemberton, L.; Sheikh, H.; Chan, C.; Faivre-Finn, C.	130: Routine implementation of electronic patient reported outcomes (ePRO) in lung cancer patients	2017	Lung Cancer (01695002)	Non-EHR integration
Albert, L.; Capel, I.; García-Sáez, G.; Martín-Redondo, P.; Hernando, M. E.; Rigla, M.	Managing gestational diabetes mellitus using a smartphone application with artificial intelligence (SineDie) during the COVID-19 pandemic: Much more than just telemedicine	2020	Diabetes Research and Clinical Practice	Non-EHR integration

Authors	Title	Year	Journal	Exclusion Reason
Allen, N. A.; Zagarins, S. E.; Welch, G.	Refinement and evaluation of a comprehensive disease management program for diabetes and cardiovascular risk reduction	2012	Diabetes	Not original article
Anand, V.; McKee, S.; Dugan, T. M.; Downs, S. M.	Leveraging electronic tablets for general pediatric care: a pilot study	2015	Applied Clinical Informatics	Potential to Integrate Only
Anthony, C. A.; Polgreen, L. A.; Chounramany, J.; Foster, E. D.; Goerdt, C. J.; Miller, M. L.; Suneja, M.; Segre, A. M.; Carter, B. L.; Polgreen, P. M.	Outpatient blood pressure monitoring using bi-directional text messaging	2015	Journal of the American Society of Hypertension	Non-EHR integration
Archangelidi, O.; Abbott, J.; Bryon, M.; Cosgriff, R.; Simmonds, N.; Duckers, J.; Bell, N.; Wildman, M.; Withers, N.; Orchard, C.; Bilton, D.; Carr, S. B.	Quality of life in patients with CF using three online research questionnaires: A feasibility study	2019	Pediatric Pulmonology	Non-EHR integration
Arens-Volland, A.; Feidert, F.; Herbst, R.; MÃ¶sges, R.; RÃ¶sch, N.	Use of electronic patient diaries supports diagnosis of food allergy and diet management	2011	Clinical and Translational Allergy	Not original article
Arnold, J.; Tudorascu, D. L.; McTigue, K. M.; Bryce, C. L.; Simkin-Silverman, L. R.; Hess, R.; Fischer, G.; Conroy, M.	Online lifestyle tracking only improves weight outcomes in conjunction with coaching support: Results from the maintain-PC study	2018	Journal of General Internal Medicine	Not original article
Arvanitis, M.; Moore, A.; Hur, S.; Curtis, L. M.; Ladner, D.; Wolf, M. S.	Online assessments of medication adherence and risks for inadequate adherence to critical medications in ambulatory populations	2019	Journal of General Internal Medicine	Insufficient data
Aschettino, L.; Baldwin, K.; Friedman, B.; Grady, R.; Grebner, L.; Hennings, M. E.; Kadlec, L.; Kirby, A.; Meyer, M.; O'Dell, R. M.; Pearson, S.; Roberson, J.; Rulon, V.; Schoeffel, B.; Smith, A.; Tegen, A.; Washington, L.	Including Patient-Generated Health Data in Electronic Health Records	2015	Journal of AHIMA	Wrong study design
Ashley, L.; Jones, H.; Forman, D.; Newsham, A.; Brown, J.; Downing, A.; Velikova, G.; Wright, P.	Feasibility test of a UK-scalable electronic system for regular collection of patient-reported outcome measures and linkage with clinical cancer registry data: the electronic Patient-reported Outcomes from Cancer Survivors (ePOCS) system	2011	BMC Medical Informatics and Decision Making	Non-EHR integration
Atreja, A.; Khan, S.; Rogers, J. D.; Otobo, E.; Patel, N. P.; Ullman, T.; Colombel, J. F.; Moore, S.; Sands, B. E.; Health, Promise Consortium Group	Impact of the Mobile HealthPROMISE Platform on the Quality of Care and Quality of Life in Patients With Inflammatory Bowel Disease: Study Protocol of a Pragmatic Randomized Controlled Trial	2015	JMIR Research Protocols	Non-EHR integration
Aung, T.; Sharpe, R.; Manhas, R.; Kyle, S.	Use of a web-based Rheumatology patient management portal	2019	Annals of the Rheumatic Diseases	Non-EHR integration
Austin, L.; Sanders, C.; Dixon, W.	Patients' experiences of using a smartphone app for remote monitoring of rheumatoid arthritis integrated into the electronic medical record and its impact on consultations	2017	Rheumatology (United Kingdom)	Non-EHR integration
Austin, L.; Sanders, C.; Dixon, W.	Patients' experiences of remote monitoring of rheumatoid arthritis using a smartphone app	2017	Annals of the Rheumatic Diseases	Not original article

Authors	Title	Year	Journal	Exclusion Reason
Austin, L.; Sanders, C.; Dixon, W. G.	Patients' experiences of using a smartphone app for remote monitoring of rheumatoid arthritis, integrated into the electronic medical record, and its impact on consultations	2016	Arthritis and Rheumatology	Not original article
Austin, L.; Sharp, C. A.; van der Veer, S. N.; Machin, M.; Humphreys, J.; Mellor, P.; McCarthy, J.; Ainsworth, J.; Sanders, C.; Dixon, W. G.	Providing 'the bigger picture': benefits and feasibility of integrating remote monitoring from smartphones into the electronic health record	2019	Rheumatology	Potential to Integrate Only
Austin, L.; Sharp, C. A.; van der Veer, S. N.; Machin, M.; Humphreys, J.; Mellor, P.; McCarthy, J.; Ainsworth, J.; Sanders, C.; Dixon, W. G.	Providing 'the bigger picture': Benefits and feasibility of integrating remote monitoring from smartphones into the electronic health record	2020	Rheumatology (United Kingdom)	Duplicate
Austin, Lynn; Sharp, Charlotte A.; Veer, Sabine N. van der; Machin, Matthew; Humphreys, John; Mellor, Peter; McCarthy, Jill; Ainsworth, John; Sanders, Caroline; Dixon, William G.	Providing 'the bigger picture': benefits and feasibility of integrating remote monitoring from smartphones into the electronic health record: Findings from the Remote Monitoring of Rheumatoid Arthritis (REMORA) study	2020	Rheumatology	Research study
Avery, K. N. L.; Richards, H. S.; Portal, A.; Reed, T.; Harding, R.; Carter, R.; Bamforth, L.; Absolom, K.; O'Connell Francischetto, E.; Velikova, G.; Blazeby, J. M.	Developing a real-time electronic symptom monitoring system for patients after discharge following cancer-related surgery	2019	BMC Cancer	Not original article
Avery, K.; Richards, H.; Portal, A.; Reed, T.; Harding, R.; Carter, R.; Absolom, K.; Velikova, G.; Blazeby, J.	Systematic electronic capture of patient reported outcomes after cancer surgery: A valuable adjunct to post-operative care	2019	European Journal of Surgical Oncology	Not original article
Avery, K.; Richards, H.; Portal, A.; Reed, T.; Harding, R.; Carter, R.; Absolom, K.; Velikova, G.; Blazeby, J.	Feasibility of digital self-report PRO data for monitoring adverse events after discharge following major abdominal cancer surgery: the eRAPID study	2018	Quality of Life Research	Not original article
Ayers, D. C.; Zheng, H.; Franklin, P. D.	Integrating patient-reported outcomes into orthopaedic clinical practice: proof of concept from FORCE-TJR	2013	Clinical Orthopaedics and Related Research	Potential to Integrate Only
Bae, W. K.; Kwon, J.; Lee, H. W.; Lee, S. C.; Song, E. K.; Shim, H.; Ryu, K. H.; Song, J.; Seo, S.; Yang, Y.; Park, J. H.; Lee, K. H.; Han, H. S.	Feasibility and accessibility of electronic patient-reported outcome measures using a smartphone during routine chemotherapy: a pilot study	2018	Supportive Care in Cancer	Non-EHR integration
Baig, M. M.; GholamHosseini, H.	Wireless remote patient monitoring in older adults	2013	2013 35th Annual International Conference of the IEEE Engineering in Medicine and Biology Society	Potential to Integrate Only
Basch, E.; Abernethy, A. P.	Supporting clinical practice decisions with real-time patient-reported outcomes	2011	Journal of Clinical Oncology	Wrong study design
Bayliss, E. A.; Tabano, H. A.; Gill, T. M.; Anzuoni, K.; Tai-Seale, M.; Allore, H. G.; Ganz, D. A.; Dublin, S.; Gruber-Baldini, A. L.; Adams, A. L.; Mazor, K. M.	Data Management for Applications of Patient Reported Outcomes	2018	EGEMS	Wrong study design
Beadnall, H. N.; Kuppanda, K. E.; O'Connell, A.; Hardy, T. A.; Reddel, S. W.; Barnett, M. H.	Tablet-based screening improves continence management in multiple sclerosis	2015	Annals of Clinical & Translational Neurology	Not PGHD

Authors	Title	Year	Journal	Exclusion Reason
Bell, K.; Warnick, E.; Nicholson, K.; Ulcoq, S.; Kim, S. J.; Schroeder, G. D.; Vaccaro, A.	Patient Adoption and Utilization of a Web-Based and Mobile-Based Portal for Collecting Outcomes After Elective Orthopedic Surgery	2018	American Journal of Medical Quality	Non-EHR integration
Benson, G.; Sidebottom, A. C.; Sillah, A.; Vock, D. M.; Vacquier, M. C.; Miedema, M. D.; VanWormer, J. J.	Population-level changes in lifestyle risk factors for cardiovascular disease in the Heart of New Ulm Project	2019	Preventive Medicine Reports	Not PGHD
Bergquist, T.; Buie, R. W.; Li, K.; Brandt, P.	Heart on FHIR: Integrating Patient Generated Data into Clinical Care to Reduce 30 Day Heart Failure Readmissions (Extended Abstract)	2017	AMIA ... Annual Symposium proceedings. AMIA Symposium	Potential to Integrate Only
Bernhard, L.; Coffman, J.; Elberson, J.; Hodgeman, B.; Starn, J.; Winners, S.; Winslow, V.; Rasmussen, P.; Majhail, N. S.	Pilot Study of Home Vitals and Activity Monitoring for Allogeneic Hematopoietic Cell Transplant Recipients	2019	Biology of Blood and Marrow Transplantation	Insufficient data
Bidmead, E.; Marshall, A.	A case study of stakeholder perceptions of patient held records: the Patients Know Best (PKB) solution	2016	Digital Health	Potential to Integrate Only
Binstock, A.; Lemon, L.; Hauspurg, A.; Larkin, J.; Watson, A.; Quinn, B.; Cabrera, C.; Redman, E.; Javaid, A.; Beigi, R.; Simhan, H.	129: The effect of a remote blood pressure monitoring program on postpartum healthcare utilization	2020	American Journal of Obstetrics and Gynecology	Non-EHR integration
Blackhall, L.; Read, P.; Davis, M. A.; Stukenborg, G.	Making my course better: Using patient reported outcomes to integrate palliative care acrossthe spectrum of care for patients with advanced cancer	2014	Journal of Pain and Symptom Management	Wrong setting
Blaivas, J.; Poon, M.; Li, E.; Manyevitch, R.; Thomas, D.	A new paradigm for outpatient diagnosis and treatment of lower urinary tract symptoms utilizing a mobile app/software platform and remote patient visits: Feasibility study	2019	Neurourology and Urodynamics	Potential to integrate only
Bonet, L.; Llacer, B.; Arce, D.; Blanquer, I.; Hernandez, M.; Cañete, C.; Sanjuán, J.	Filling the gap between research and clinical practice: A new app for patients with first episode of psychosis	2019	Schizophrenia Bulletin	Insufficient data
Bonet, L.; Torous, J.; Arce, D.; Blanquer, I.; Sanjuan, J.	ReMindCare, an app for daily clinical practice in patients with first episode psychosis: A pragmatic real-world study protocol	2020	Early Interv Psychiatry	Potential to integrate only
Bosch, B.; Hartman, S.; Caldarello, L.; Denny, D.	Integrating patient-reported outcomes data into the electronic health record	2018	Journal of Clinical Oncology	Insufficient data
Bourke, A.; O'Hanlon, S.; Helliwell, T.; Cooper, M.; Mullane, M.; Meleck, S.; Hiller, J.; Dhanjal, J.	Initiation of an innovative study combining digital patient generated data with health records to evolve understanding of Back pain	2019	Pharmacoepidemiology and Drug Safety	Non-EHR integration
Brister, L. E.; Metheny, L.; Baer, L. K.; Gallogly, M.	Obtaining patient reported outcome data in the era of electronic medical records	2018	Biology of Blood and Marrow Transplantation	Insufficient data
Brooks Taylor, Lisa	Preparing for Patient-Generated Documents...Initiatives call for incorporating patient-generated data in the EHR	2013	Journal of AHIMA	Wrong study design
Brookshire-Gay, K.; LaLonde, L.; Byrd, M.; Neenan, A.; Seyedsalehi, S.; Hanauer, D. A.; Choi, S. W.; Hoodin, F.	Health Information Technology Utilization by Adolescent and Young Adult Aged Inpatients Undergoing Hematopoietic Cell Transplantation	2020	Journal of Adolescent Young Adult Oncology	Inpatient setting

Authors	Title	Year	Journal	Exclusion Reason
Brunelli, C.; Borreani, C.; Caraceni, A.; Roli, A.; Bellazzi, M.; Lombi, L.; Zito, E.; Pellegrini, C.; Spada, P.; Kaasa, S.; Foschi, A. M.; Apolone, G.; Belli, F.; Capri, G.; Casali, P.; Corradini, P.; De Braud, F.; Folli, S.; Garassino, M.; Licitra, L.; Nicolai, N.; Platania, M.; Procopio, G.; Salvioni, R.; Valdagni, R.	PATIENT VOICES, a project for the integration of the systematic assessment of patient reported outcomes and experiences within a comprehensive cancer center: A protocol for a mixed method feasibility study	2020	Health and Quality of Life Outcomes	Potential to integrate only
Bryce, C. L.; Tomko, H.; McTigue, K. M.; Arnold, J.; Fischer, G.; Gibbs, B. B.; Hess, R.; Huber, K.; Simkin-Silverman, L.; Tudorascu, D.; Conroy, M.	Cost-effectiveness of an electronic health record-based intervention to prevent weight regain	2019	Journal of General Internal Medicine	Insufficient data
Bui, A. A. T.; Hosseini, A.; Rocchio, R.; Jacobs, N.; Ross, M. K.; Okelo, S.; Lurmann, F.; Eckel, S.; Dzubur, E.; Dunton, G.; Gilliland, F.; Sarrafzadeh, M.; Habre, R.	Biomedical REAl-Time Health Evaluation (BREATHE): toward an mHealth informatics platform	2020	JAMIA open	Non-EHR integration
Buzaglo, J. S.; Skinner, K. E.; Stepanski, E.; Tankersley, C.; Schwartzberg, L. S.	Understanding patient advance directives status in a community oncology practice using an electronic patient-reported outcomes (ePRO) system	2019	Journal of Clinical Oncology	Insufficient data
Buzaglo, J. S.; Skinner, K.; Stepanski, E.; Decker, V.; Schwartzberg, L. S.	Capturing patient advance directives status in a community oncology practice using an electronic patient-reported outcomes (ePRO) system	2019	Journal of Clinical Oncology	Not Patient Generated Health Data
Buzaglo, J. S.; Stepanski, E.; Joiner, M.; Taylor, D.; Musallam, A.; Richey, S. S.; Schwartzberg, L. S.; Vanderwalde, A. M.; Decker, V. B.	Using an ePRO tool to help meet quality metric reporting standards: Screening for tobacco usage and falls risk	2020	Journal of Clinical Oncology	Wrong setting
Buzaglo, J. S.; Stepanski, E.; Joiner, M.; Taylor, D.; Tankersley, C.; Vanderwalde, A. M.; Schwartzberg, L. S.	Using an ePRO tool to help meet quality metrics in a clinical oncology practice	2019	Journal of Clinical Oncology	Insufficient data
Bydon, M.; Goyal, A.; Wolff, K.; Illies, A. C.; Alvi, M.; Goncalves, S.; Dhanoerkar, A.; Biedermann, A.; Paul, T.; Cheville, A.; Nyman, M.	Feasibility of using computerized adaptive testing to capture patient reported outcomes in an outpatient setting: A pilot evaluation of promis-cat in neurosurgery	2020	Journal of Neurosurgery	Not Patient Generated Health Data
Cadmus-Bertram, Lisa; Tevaarwerk, Amye J.; Sesto, Mary E.; Gangnon, Ronald; Van Remortel, Brittany; Date, Preshita	Building a physical activity intervention into clinical care for breast and colorectal cancer survivors in Wisconsin: a randomized controlled pilot trial	2019	Journal of Cancer Survivorship	Research study
Cahn, A.; Akirov, A.; Raz, I.	Digital health technology and diabetes management	2018	Journal of Diabetes	Not original article
Capozza, K.; Woolsey, S.; Georgsson, M.; Black, J.; Bello, N.; Lence, C.; Oostema, S.; North, C.	Going mobile with diabetes support: a randomized study of a text message-based personalized behavioral intervention for type 2 diabetes self-care	2015	Diabetes Spectrum	Non-EHR integration

Authors	Title	Year	Journal	Exclusion Reason
Carrasco, E.; Sanchez, E.; Artetxe, A.; Toro, C.; Grana, M.; Guijarro, F.; Susperregui, J. M.; Aguirre, A.	Hygehos Home: an innovative remote follow-up system for chronic patients	2014	Studies in Health Technology and Informatics	Not original article
Carroll, R.; Hassan, I.; Ahad, S.; El Haoud, M.; Goffredo, P.	Feasibility and utility of a telemedicine protocol for post discharge follow-up in patients undergoing Bariatric surgery	2019	Surgery for Obesity and Related Diseases	Insufficient data
Casper, G. R.; Brennan, P. F.	Project HealthDesign: a preliminary program-level report	2013	AMIA ... Annual Symposium Proceedings/AMIA Symposium	Potential to Integrate Only
Castellucci, Maria	NYC hospital prioritizes collection of patient-reported outcome data	2017	Modern Healthcare	Not original article
Chand, D. H.; Bednarz, D.	Daily remote peritoneal dialysis monitoring: an adjunct to enhance patient care	2008	Peritoneal Dialysis International	Non-EHR integration
Cho, S. W.; Wee, J. H.; Yoo, S.; Heo, E.; Ryu, B.; Kim, Y.; Lee, J. S.; Kim, J. W.	Effect of Lifestyle Modification Using a Smartphone Application on Obesity With Obstructive Sleep Apnea: A Short-term, Randomized Controlled Study	2018	Clinical and Experimental Otorhinolaryngology	Insufficient data
Chung, A. E.; Basch, E. M.	Incorporating the patient's voice into electronic health records through patient-reported outcomes as the "review of systems"	2015	Journal of the American Medical Informatics Association	Wrong study design
Chung, A.; Stover, A. M.; Wagner, L. I.; LeBlanc, T. W.; Topalaglu, U.; Zafar, Y.; Zullig, L. L.; Smeltzer, P.; Basch, E. M.	Harmonization of patient-reported outcomes into EHRs at four cancer hospital outpatient clinics for patient care and quality assessment	2017	Journal of Clinical Oncology	Not original article
Clark, K.; Matthews, K.; Strowbridge, R.; Rinehart, R.; Smith, D.; Loscalzo, M.	Implementing touch-screen technology to enhance recognition of distress: An integrated approach to patient care	2009	Psycho-Oncology	Wrong study design
Clark, R. M.; del Carmen, M. G.	Implementation of routine clinical collection of electronic patient reported outcomes in patients with gynecologic malignancy	2019	Gynecologic Oncology	Not original article
Coenen, S.; Weyts, E.; Geens, P.; Nijns, E.; Van Durm, R.; Ferrante, M.; Vermeire, S.; Van Den Bosch, B.; Van Assche, G.	A prospective trial to evaluate the feasibility of a mobile app in patients with inflammatory bowel disease under maintenance therapy	2018	Journal of Crohn's and Colitis	Insufficient data
Coons, J. C.; Patel, R.; Coley, K. C.; Empey, P. E.	Design and testing of Medivate, a mobile app to achieve medication list portability via Fast Healthcare Interoperability Resources	2019	Journal of the American Pharmacists Association	EHR to App Integration Only
Cox, C. E.; Jones, D. M.; Reagan, W.; Key, M. D.; Chow, V.; McFarlin, J.; Casarett, D.; Creutzfeldt, C. J.; Docherty, S. L.	Palliative Care Planner: A Pilot Study to Evaluate Acceptability and Usability of an Electronic Health Records System-integrated, Needs-targeted App Platform	2018	Annals of the American Thoracic Society	Non-EHR integration
Cunningham, M.; Cunningham, P. M.	MHealth4Afrika Pilot Validation in Healthcare Facilities in Ethiopia, Kenya and Malawi	2019	2019 IEEE Global Humanitarian Technology Conference	Integrated EHR/EMR data to app
Cutts, T.; Holmes, S.; Kedar, A.; Beatty, K.; K. Mohammad M; Abell, T.	Twenty-five years of advocacy for patients with gastroparesis: support group therapy and patient reported outcome tool development	2016	BMC Gastroenterology	Non-EHR integration
Dae-Young, Kim; Sun-ho, Hwang; Min-Gyu, Kim; Joon-Hyun, Song; Sin-Woong, Lee; Il Kon, Kim	Development of Parkinson Patient Generated Data Collection Platform Using FHIR and IoT Devices...The 16 World Congress of Medical and Health Informatics: Precision Healthcare Through Informatics (MedInfo2017) was held in Hangzhou, China from August 21st to 25th, 2017	2018	Studies in Health Technology and Informatics	Potential to Integrate Only

Authors	Title	Year	Journal	Exclusion Reason
Daly, B.; Kuperman, G.; Zervoudakis, A.; Baldwin Medsker, A.; Roy, A.; Ro, A. S.; Arenas, J.; Yanamandala, H. V.; Kottamasu, R.; Salvaggio, R.; Holland, J.; Hirsch, S.; Walters, C. B.; Lauria, T.; Chow, K.; Begue, A.; Rozenshteyn, M.; Zablocki, M.; Dhami, A. K.; Silva, N.; Brown, E.; Katzen, L. L.; Chiu, Y. O.; Perry, C.; Sokolowski, S.; Wagner, I.; Veach, S. R.; Grisham, R. N.; Dang, C. T.; Reidy-Lagunes, D. L.; Simon, B. A.; Perchick, W.	InSight Care Pilot Program: Redefining Seeing a Patient	2020	JCO Oncology Practice	Research study
Daly, R. M.; Kuperman, G.; Zervoudakis, A.; Ro, A.; Roy, A.; Baldwin, A.; Salvaggio, R.; Holland, J. C.; Chow, K.; Lauria, T.; Rozenshteyn, M.; Zablocki, M.; Chiu, Y. O.; Silva, N.; Perry, C.; Sokolowski, S.; Wagner, I.; Simon, B. A.; Reidy, D. L.; Perchick, W.	Pilot program of remote monitoring for high-risk patients on antineoplastic treatment	2020	Journal of Clinical Oncology	Non-EHR integration
Danis, C. M.	Incorporating patient generated health data into chronic disease management: A human factors approach	2015	Unknown	Not original article
de Bruin, J. S.; Schuh, C.; Seeling, W.; Luger, E.; Gall, M.; Hutterer, E.; Kornek, G.; Ludvik, B.; Hoppichler, F.; Schindler, K.	Assessing the feasibility of a mobile health-supported clinical decision support system for nutritional triage in oncology outpatients using Arden Syntax	2018	Artificial Intelligence in Medicine	Non-EHR integration
de Jong, J. M.; Ogink, P. A.; van Bunningen, C. G.; Driessen, R. J.; Engelen, L. J.; Heeren, B.; Bredie, S. J.; van de Belt, T. H.	A Cloud-Based Virtual Outpatient Clinic for Patient-Centered Care: Proof-of-Concept Study	2018	Journal of Medical Internet Research	Non-EHR integration
De Toledo, P.; Lalinde, W.; Del Pozo, F.; Thurber, D.; Jimenez-Fernandez, S.	Interoperability of a mobile health care solution with electronic healthcare record systems	2006	2006 Annual International Conference of the IEEE Engineering in Medicine and Biology Society	Potential to Integrate Only
Deal, C.; Abelson, A.; Calabrese, L. H.; Strnad, G.; Katzan, I.; Husni, M. E.	Development and implementation of a patient-reported outcomes measurement information system (myrheum)	2018	Arthritis and Rheumatology	Insufficient data
Deng, Y.; Burkle, T.; Holm, J.; Zetz, E.; Denecke, K.	Last Mile Towards Efficient Healthcare Delivery in Switzerland: eHealth Enabled Applications Could Speed Up the Care Process	2018	Studies in Health Technology and Informatics	Non-EHR integration
Desai, S.; Stevens, E.; Emani, S.; Meyers, P.; Iversen, M.; Solomon, D. H.	Improving Quality of Care in Rheumatoid Arthritis Through Mobile Patient-Reported Outcome Measurement: Focus Group Study	2020	JMIR Formative Research	Not Patient Generated Health Data
Dhruva, S. S.; Ross, J. S.; Akar, J. G.; Caldwell, B.; Childers, K.; Chow, W.; Ciaccio, L.; Coplan, P.; Dong, J.; Dykhoff, H. J.; Johnston, S.; Kellogg, T.; Long, C.; Noseworthy, P. A.; Roberts, K.; Saha, A.; Yoo, A.; Shah, N. D.	Aggregating multiple real-world data sources using a patient-centered health-data-sharing platform	2020	Nature Partner Journals	Non-EHR integration

Authors	Title	Year	Journal	Exclusion Reason
Dixon, B. E.; Alzeer, A. H.; Phillips, E. O.; Marrero, D. G.	Integration of Provider, Pharmacy, and Patient-Reported Data to Improve Medication Adherence for Type 2 Diabetes: A Controlled Before-After Pilot Study	2016	JMIR Medical Informatics	Potential to Integrate Only
Donado, C.; Lobo, K.; Berde, C. B.; Bourgeois, F. T.	Developing a pediatric pain data repository	2020	JAMIA open	Non-EHR integration
Duncan, P. W.; Abbott, R. M.; Rushing, S.; Johnson, A. M.; Condon, C. N.; Lycan, S. L.; Lutz, B. J.; Cummings, D. M.; Pastva, A. M.; D'Agostino, R. B.; Stafford, J. M.; Amoroso, R. M.; Jones, S. B.; Psioda, M. A.; Gesell, S. B.; Rosamond, W. D.; Prvu-Bettger, J.; Sissine, M. E.; Boynton, M. D.; Bushnell, C. D.	COMPASS-CP: An Electronic Application to Capture Patient-Reported Outcomes to Develop Actionable Stroke and Transient Ischemic Attack Care Plans	2018	Circulation. Cardiovascular quality and outcomes	Potential to integrate only
Edelen, C.; Spencer, L.	Implementation of electronic patient-reported outcomes (PRO) in outpatient oncology palliative medicine (PM) consults	2018	Journal of Pain and Symptom Management	Insufficient data
Eden, Karen B.; Ivlev, Ilya; Bensching, Katherine L.; Franta, Gabriel; Hersh, Alyssa R.; Case, James; Fu, Rongwei; Nelson, Heidi D.	Use of an Online Breast Cancer Risk Assessment and Patient Decision Aid in Primary Care Practices	2020	Journal of Women's Health	Non-EHR integration
El-Sappagh, S.; Ali, F.; Hendawi, A.; Jang, J. H.; Kwak, K. S.	A mobile health monitoring-and-treatment system based on integration of the SSN sensor ontology and the HL7 FHIR standard	2019	BMC Medical Informatics and Decision Making	Wrong study design
Espinoza, J.; Shah, P.; Raymond, J.	Integrating Continuous Glucose Monitor Data Directly into the Electronic Health Record: Proof of Concept	2020	Diabetes Technol Ther	Wrong study design
Esteban, Cristóbal; Esteban-Aizpiri, Cristóbal; Aramburu, Amaia; Moraza, Francisco Javier; Sancho, Fernando; Tovar, Maria Dolores; Goiria, Begoña; Aguirre, Urko; Aburto, Myriam; Quintana, José María	Telehealth and machine learning for COPD patient care	2019	International Journal of Integrated Care	Non-EHR integration
Fanucci, Luca; Saponara, Sergio; Bacchillone, Tony; Donati, Massimiliano; Barba, Pierluigi; Sanchez-Tato, Isabel; Carmona, Cristina	Sensing Devices and Sensor Signal Processing for Remote Monitoring of Vital Signs in CHF Patients	2013	IEEE Transactions on Instrumentation & Measurement	Wrong study design
Farr-Wharton, G.; Li, J.; Hussain, M. S.; Freyne, J.	Mobile Supported Health Services: Experiences in Orthopaedic Care	2020	2020 IEEE 33rd International Symposium on Computer-Based Medical Systems	Non-EHR integration
Fayanju, O. M.; Mayo, T. L.; Spinks, T. E.; Lee, S.; Barcenas, C. H.; Smith, B. D.; Giordano, S. H.; Hwang, R. F.; Ehlers, R. A.; Selber, J. C.; Walters, R.; Tripathy, D.; Hunt, K. K.; Buchholz, T. A.; Feeley, T. W.; Kuerer, H. M.	Value-Based Breast Cancer Care: A Multidisciplinary Approach for Defining Patient-Centered Outcomes	2016	Annals of Surgical Oncology	Potential to Integrate Only
Finkelstein, J.; Hripcsak, G.; Cabrera, M. R.	Patients' acceptance of Internet-based home asthma telemonitoring	1998	2012 Annual International Conference of the IEEE Engineering in Medicine and Biology Society	Non-EHR integration

Authors	Title	Year	Journal	Exclusion Reason
Fioravanti, A.; Fico, G.; Arredondo, M. T.; Leuteritz, J. P.	A mobile feedback system for integrated E-health platforms to improve self-care and compliance of diabetes mellitus patients	2011	2011 Annual International Conference of the IEEE Engineering in Medicine and Biology Society	Wrong study design
Fiore, J. F.; Feldman, L. S.	Tracking Postoperative Recovery-Making a Case for Smartphone Technology	2020	JAMA Surgery	Editorial/review
Fisch, M. J.; Chung, A. E.; Accordino, M. K.	Using Technology to Improve Cancer Care: Social Media, Wearables, and Electronic Health Records	2016	American Society of Clinical Oncology Educational Book	Wrong study design
Flukes, S.; Cracchiolo, J.; Geer, E.; Goldstein, D.; De Almeida, J.; Tabar, V.; Cohen, M. A.	Quality from the patient's perspective: Implementation of an established patient-reported outcome platform in a multidisciplinary skull base tumor clinic	2020	Journal of Neurological Surgery, Part B Skull Base	Insufficient data
Forman, M.; Leatherwood, C.; Xu, C.; Ko, E.; Lu, B.; Iversen, M. D.; Solomon, D.; Desai, S.	Implementation of a treat-to-target quality improvement program for rheumatoid arthritis management using real-time patient reported outcome measures	2018	Arthritis and Rheumatology	Insufficient data
Franklin, P.; Chenok, K.; Lavalee, D.; Love, R.; Paxton, L.; Segal, C.; Holve, E.	Framework To Guide The Collection And Use Of Patient-Reported Outcome Measures In The Learning Healthcare System	2017	EGEMS	Not original article
French, K. E.; Feeley, T. W.; Andrabi, T. A.; Guzman, A. B.; Calhoun, J. D.	Cancer patients' answers to surveys: Incorporation into the electronic health record (EHR) can decrease manual data entry and increase patient-centered information	2017	Journal of Clinical Oncology	Insufficient data
Fritz, F.; Balhorn, S.; Riek, M.; Breil, B.; Dugas, M.	Qualitative and quantitative evaluation of EHR-integrated mobile patient questionnaires regarding usability and cost-efficiency	2012	International Journal of Medical Informatics	Wrong setting
Fritz, F.; Dugas, M.	Are physicians interested in the quality of life of their patients? usage of EHR-integrated patient reported outcomes data	2013	Studies in Health Technology and Informatics	Wrong setting
Fritz, Fleur; Dugas, Martin	Are Physicians Interested in the Quality of Life of their Patients? Usage of EHR-integrated Patient Reported Outcomes Data...MEDINFO 2013	2013	Studies in Health Technology and Informatics	Wrong setting
Fung, C.; Peckham, J.; Porto, M.; Lin, P. J.; Sahasrabudhe, D. M.; Guancial, E. A.; Ky, B.; Storozynsky, E.; Janelsins, M. C.; Heckler, C. E.; Bruckner, L. B.; Mohile, S. G.; Mustian, K. M.	Feasibility of an electronic implementation method of an evidence-based exercise intervention among testicular cancer survivors (TCS)	2017	Journal of Clinical Oncology	Not original article
Fung, C.; Peckham, J.; Porto, M.; Lin, P. L.; Sahasrabudhe, D. M.; Guancial, E. A.; Ky, B.; Storozynsky, E.; Janelsins, M. C.; Heckler, C. E.; Culakova, E.; Bruckner, L. B.; Mohile, S. G.; Mustian, K. M.	Feasibility of utilizing a novel mhealth platform to deliver an evidence-based exercise intervention among testicular cancer survivors (TCS)	2017	Journal of Clinical Oncology	Insufficient data
Gabriel, P. E.; Kaufmann, T. L.; Blauch, A. N.; Pucci, D. A.; Jacobs, L. A.; Bekelman, J. E.; Shulman, L. N.; Takvorian, S. U.	Adherence to remote versus clinic-based collection of patientreported outcomes in patients with advanced lung cancer	2020	Journal of Clinical Oncology	Insufficient data
Gadgil, M. D.; Anderson, N.; Gillette, D.; Feldman, M. D.; Riedl, A.; Dharmar, M.; Satterfield, J.; Lozano, A.; Lehman, M.; Haddad, D.; Lindeman, D.; Sim, I.	Using patient-reported and mobile health data in practice: Focus on hypertension and depression	2018	Journal of General Internal Medicine	Potential to Integrate Only

Authors	Title	Year	Journal	Exclusion Reason
Galligioni, E.; Caramatti, S.; Sandri, M.; Galvagni, M.; Zanolli, D.; SannicolÃ², M.; Ferro, A.; Bragantini, L.; Maines, F.; Trentin, C.; Pellegrini, C.; Sandri, D.; Santi, J.; Caffo, O.	Integrating mobile Health (mHealth) information technology for the safe administration of chemotherapy (CT)	2015	Annals of Oncology	Not PGHD
Galper, A.; Shamai-Rosler, O.; Stanger, V.; Zimlichman, E.	PRO (Patient Reported Outcomes) implementation at Sheba Medical Center	2019	Israel Journal of Health Policy Research	Insufficient data
Garcia, S. F.; Wortman, K.; Cella, D.; Wagner, L. I.; Bass, M.; Kircher, S.; Pearman, T.; Penedo, F. J.	Implementing electronic health recordâ€"integrated screening of patient-reported symptoms and supportive care needs in a comprehensive cancer center	2019	Cancer	Not original article
Gay, V.; Leijdekkers, P.	Bringing Health and Fitness Data Together for Connected Health Care: Mobile Apps as Enablers of Interoperability	2015	Journal of Medical Internet Research	Potential to Integrate Only
Gay, V.; Leijdekkers, P.; Gill, A.; Felix Navarro, K.	Le Bon Samaritain: A Community-Based Care Model Supported by Technology	2015	Studies in Health Technology and Informatics	Non-EHR integration
Gaynor, M.; Myung, D.; Gupta, A.; Moulton, S.	A standardised pre-hospital electronic patient care system	2009	International Journal of Electronic Healthcare	Not PGHD
Genes, N.; Violante, S.; Cetrangol, C.; Rogers, L.; Schadt, E. E.; Chan, Y. Y.	From smartphone to EHR: a case report on integrating patient-generated health data	2018	Npj Digital Medicine	Wrong study design
Gensheimer, S. G.; Wu, A. W.; Snyder, C. F.; Pro-Ehr Users' Guide Steering Group; Pro-Ehr Users' Guide Working Group	Oh, the Places We'll Go: Patient-Reported Outcomes and Electronic Health Records	2018	The Patient: Patient-Centered Outcomes Research	Not original article
Gifford, A. H.; Snide, J. A.; Sabadosa, K.	Use of an electronic medical record template to capture clinical and patient reported data for the CF foundation patient registry	2019	Pediatric Pulmonology	Insufficient data
Gilbert, A.; Sebag-Montefiore, D.; Davidson, S. E.; Santorelli, G.; Velikova, G.	Electronic and paper collection of patient-reported toxicity in patients treated with pelvic radiation therapy: A prospective feasibility study	2016	International Journal of Radiation Oncology	Insufficient data
Giordanengo, A.; Arsand, E.; Woldaregay, A. Z.; Bradway, M.; Grottland, A.; Hartvigsen, G.; Granja, C.; Torsvik, T.; Hansen, A. H.	Design and Prestudy Assessment of a Dashboard for Presenting Self-Collected Health Data of Patients With Diabetes to Clinicians: Iterative Approach and Qualitative Case Study	2019	JMIR Diabetes	Potential to Integrate Only
Giordanengo, A.; Bradway, M.; GrÃ¸ttland, A.; Hartvigsen, G.; Arsand, E.	A fhir-based data flow enabling patients with diabetes to share self-collected data with the norwegian national healthcare systems and electronic health record systems	2018	Diabetes Technology and Therapeutics	Potential to Integrate Only
Girgis, A.; Delaney, G. P.; Arnold, A.; Miller, A. A.; Levesque, J. V.; Kaadan, N.; Carolan, M. G.; Cook, N.; Masters, K.; Tran, T. T.; Sandell, T.; Durcinoska, I.; Gerges, M.; Avery, S.; Ng, W.; Della-Fiorentina, S.; Dhillon, H. M.; Maher, A.	Development and Feasibility Testing of PROMPT-Care, an eHealth System for Collection and Use of Patient-Reported Outcome Measures for Personalized Treatment and Care: A Study Protocol	2016	JMIR Research Protocols	Wrong study design
Girgis, A.; Durcinoska, I.; Arnold, A.; Delaney, G. P.	Interpreting and Acting on the PRO Scores From the Patient-reported Outcomes for Personalized Treatment and Care (PROMPT-Care) eHealth System	2019	Medical Care	Excluded Original

Authors	Title	Year	Journal	Exclusion Reason
Girgis, A.; Durcinoska, I.; Gerges, M.; Kaadan, N.; Arnold, A.; Descallar, J.; Delaney, G. P.; P. ROMPT-Care Program Group	Study protocol for a controlled trial of an eHealth system utilising patient reported outcome measures for personalised treatment and care: PROMPT-Care 2.0	2018	BMC Cancer	Wrong study design
Girgis, A.; Durcinoska, I.; Levesque, J. V.; Gerges, M.; Sandell, T.; Arnold, A.; Delaney, G. P.; P. ROMPT-Care Program Group	eHealth System for Collecting and Utilizing Patient Reported Outcome Measures for Personalized Treatment and Care (PROMPT-Care) Among Cancer Patients: Mixed Methods Approach to Evaluate Feasibility and Acceptability	2017	Journal of Medical Internet Research	Not original article
Gokalp, H.; de Folter, J.; Verma, V.; Fursse, J.; Jones, R.; Clarke, M.	Integrated Telehealth and Telecare for Monitoring Frail Elderly with Chronic Disease	2018	Telemedicine journal and e-health : the official journal of the American Telemedicine Association	Non-EHR integration
Gold, H. T.; Karia, R. J.; Link, A.; Lebwohl, R.; Zuckerman, J. D.; Errico, T. J.; Slover, J. D.; Buckland, A. J.; Mann, D. M.; Cantor, M. N.	Implementation and early adaptation of patient-reported outcome measures into an electronic health record: A technical report	2020	Health informatics journal	Duplicate
Goyal, K. K.; Davin, S. A.; Rispinto, S. C.	271. A biopsychosocial approach in the management of chronic low back pain: 2-year outcomes	2019	Spine Journal	Not Patient Generated Health Data
Graetz, I.; Anderson, J. N.; McKillop, C. N.; Stepanski, E. J.; Paladino, A. J.; Tillmanns, T. D.	Use of a web-based app to improve postoperative outcomes for patients receiving gynecological oncology care: A randomized controlled feasibility trial	2018	Gynecologic Oncology	Excluded Original
Greenwood, D. A.; Blozis, S. A.; Young, H. M.; Nesbitt, T. S.; Quinn, C. C.	Overcoming Clinical Inertia: A Randomized Clinical Trial of a Telehealth Remote Monitoring Intervention Using Paired Glucose Testing in Adults With Type 2 Diabetes	2015	Journal of Medical Internet Research	Non-EHR integration
Griffith, S. D.; Thompson, N. R.; Rathore, J. S.; Jehi, L. E.; Tesar, G. E.; Katzan, I. L.	Incorporating patient-reported outcome measures into the electronic health record for research: application using the Patient Health Questionnaire (PHQ-9)	2015	Quality of Life Research	Potential to Integrate Only
Grossi, S. M.; Dumitriu, A. L. E. W.; Lin, E.; Lee, S.; Reeves, M.; Selleck, M. J.; Lum, S. S.	Patient Reported Outcomes Via Electronic Survey (PROVES): A Pilot Study in a Breast Surgery Clinic	2020	Journal of the American College of Surgeons	Not Patient Generated Health Data
Grossman, L. V.; Mitchell, E. G.	Visualizing the Patient-Reported Outcomes Measurement Information System (PROMIS) Measures for Clinicians and Patients	2017	AMIA ... Annual Symposium Proceedings/AMIA Symposium	Wrong study design
Guattery, J. M.; Johnson, J.; Calfee, R. P.	Automation and Simplification: Drivers of Innovative Collection and Use of Patient-Reported Outcomes Data	2019	Population Health Management	Wrong study design
Guo, Y.; Lane, D. A.; Chen, Y.; Lip, G. Y. H.	Mobile health technology facilitates population screening and integrated care management in patients with atrial fibrillation	2020	European Heart Journal	Non-EHR integration
Gurland, B.; Alves-Ferreira, P. C.; Sobol, T.; Kiran, R. P.	Using technology to improve data capture and integration of patient-reported outcomes into clinical care: pilot results in a busy colorectal unit	2010	Diseases of the Colon and Rectum	Wrong setting
Gurland, B.; Ferreira, P. C. A.; Sobol, T.; Kiran, R. P.	Using technology to facilitate data capture and integration of patient reported outcomes (PRO) into colorectal surgical practice	2010	Colorectal Disease	Not original article
Gurland, B.; Ferreira, P.; Sobol, T.; Kiran, P.	Using technology to facilitate data capture and integration of Patient Reported Outcomes (PRO) into colorectal surgical practice	2010	Diseases of the Colon and Rectum	Insufficient data
Hagglund, M.; Scandurra, I.; Mostrom, D.; Koch, S.	Integration architecture of a mobile virtual health record for shared home care	2005	Studies in Health Technology and Informatics	Not PGHD
Halbert, B.; Doolin, J.; Tocci, N. X.; Zerillo, J. A.	A PROM pilot in GI oncology clinic: Outcomes and lessons in real-world implementation	2019	Journal of Clinical Oncology	Non-EHR integration

Authors	Title	Year	Journal	Exclusion Reason
Harle, C. A.; Listhaus, A.; Covarrubias, C. M.; Schmidt, S. O.; Mackey, S.; Carek, P. J.; Fillingim, R. B.; Hurley, R. W.	Overcoming barriers to implementing patient-reported outcomes in an electronic health record: a case report	2016	Journal of the American Medical Informatics Association	Wrong study design
Harle, C. A.; Marlow, N. M.; Schmidt, S. O.; Shuster, J. J.; Listhaus, A.; Fillingim, R. B.; Hurley, R. W.	The effect of EHR-integrated patient-reported outcomes on satisfaction with chronic pain care	2016	American Journal of Managed Care	Not PGHD
Harle, C.; Schmidt, S.; Fillingim, R.; Shuster, J.; Mackey, S.; Listhaus, A.; Bell, L.; Covarrubias, C.; Chisholm, T.; Hurley, R.	Toward clinical decision support for chronic pain: Integrating patient reported outcomes in an electronic health record	2015	Journal of Pain	Wrong study design
Harrington, Linda	Electronic Person-Generated Health Data	2019	AACN Advanced Critical Care	Editorial/review
Haskell, A.; Kim, T.	Implementation of Patient-Reported Outcomes Measurement Information System Data Collection in a Private Orthopedic Surgery Practice	2018	Foot and Ankle International	Not PGHD
Hassett, M. J.; Hazard, H.; Osarogiagbon, R. U.; Wong, S. L.; Bian, J. J.; Dizon, D. S.; Wedge, J.; Basch, E. M.; Mallow, J.; McCleary, N. J.; Dougherty, D. W.; Remick, S. C.; Brooks, G. A.; Mecchella, J.; Solberg, P.; Tasker, L.; Faris, N. R.; Pacheco, A.; Cronin, C.; Schrag, D.	Design of eSyM: An ePRO-based symptom management tool fully integrated in the electronic health record (Epic) to foster patient/clinician engagement, sustainability, and clinical impact	2020	Journal of Clinical Oncology	Insufficient data
Hawk, K.; Taylor, A.; Maliki, C.; Kinsman, J.; Huntley, K.; D'Onofrio, G.; Venkatesh, A.	Capturing opioid use disorder electronically and patient-reported outcomes: Results from the code-pro study	2020	Academic Emergency Medicine	Wrong setting
Herdman, David; Sharma, Helen; Simpson, Anna; Murdin, Louisa	Integrating mental and physical health assessment in a neuro-otology clinic: feasibility, acceptability, associations and prevalence of common mental health disorders	2020	Clinical Medicine	Not Patient Generated Health Data
Hermansen, N. K.; Helene Hedensted Bjerregaard, H.; Laursen, M.; Ehlers, L.	PSU39 FEASIBILITY STUDY OF USING PATIENT REPORTED OUTCOMES AND PREDICTIVE ANALYTICS IN CLINICAL DECISION SUPPORT TO ENHANCE PATIENT CENTERED CARE	2019	Value in Health	Non-EHR integration
Hernar, I.; Graue, M.; Richards, D.; Strandberg, R. B.; Nilsen, R. M.; Tell, G. S.; Haugstvedt, A.	Electronic capturing of patient-reported outcome measures on a touchscreen computer in clinical diabetes practice (the DiaPROM trial): A feasibility study	2019	Pilot and Feasibility Studies	Potential to integrate only
Hjollund, N. H.; Schougaard, L. M.; Larsen, L. P.	Systematic clinical application of Patient Reported Outcome (PRO). A new potential in clinical epidemiology	2013	European Journal of Epidemiology	Insufficient data
Hockel, R.	Practitioner Application: Developing an Implementation Strategy for Systematic Measurement of Patient-Reported Outcomes at an Academic Health Center	2020	Journal of Healthcare Management	Editorial/review
Holch, P.; Warrington, L.; Bamforth, L. C. A.; Keding, A.; Ziegler, L. E.; Absolom, K.; Hector, C.; Harley, C.; Johnson, O.; Hall, G.; Morris, C.; Velikova, G.	Development of an integrated electronic platform for patient self-report and management of adverse events during cancer treatment	2017	Annals of Oncology	Not original article

Authors	Title	Year	Journal	Exclusion Reason
Holt, Jeana M.	The Impact of Pre-visit Contextual Data Collection on Patient Activation: Results from a Randomized Control Trial	2020	Ann Arbor The University of Wisconsin - Milwaukee	Research study
Hough, S.; McDevitt, R.; Nachar, V.; Kraft, S.; Brown, A.; Christen, C.; Walters, B.; Smerage, J. B.	Chemotherapy remote care monitoring program (CRCMP): Integration of an SMS text patientreported outcome (PRO) in the electronic health record (EHR) to identify patients needing pharmacist intervention for chemotherapy-induced nausea and vomiting (CINV)	2020	Journal of Clinical Oncology	Insufficient data
Houze de l'Aulnoit, A.; Boudet, S.; Genin, M.; Gautier, P. F.; Schiro, J.; Houze de l'Aulnoit, D.; Beuscart, R.	Development of a Smart Mobile Data Module for Fetal Monitoring in E-Healthcare	2018	Journal of Medical Systems	Potential to Integrate Only
Howell, D.; Rosberger, Z.; Mayer, C.; Faria, R.; Hamel, M.; Snider, A.; Lukosius, D. B.; Montgomery, N.; Mozuraitis, M.; Li, M.; i, Pehoc Collaborative Team	Personalized symptom management: a quality improvement collaborative for implementation of patient reported outcomes (PROs) in 'real-world' oncology multisite practices	2020	Journal of PatientReported Outcomes	Non-EHR integration
Hubbard, J. M.; Grothey, A. F.; McWilliams, R. R.; Buckner, J. C.; Sloan, J. A.	Physician perspective on incorporation of oncology patient quality-of-life, fatigue, and pain assessment into clinical practice	2014	Journal of Oncology Practice	Wrong setting
Hur, S.; Lee, J.; Kim, T.; Choi, J. S.; Kang, M.; Chang, D. K.; Cha, W. C.	An Automated Fast Healthcare Interoperability Resources-Based 12-Lead Electrocardiogram Mobile Alert System for Suspected Acute Coronary Syndrome	2020	Yonsei Medical Journal	Not Patient Generated Health Data
Huynh, S.; Lee, L.; Jaffe, D.; Haskell, T.	PNS374 CLINICAL BURDEN AND HEALTH-RELATED QUALITY OF LIFE IN CAREGIVERS OF CANCER PATIENTS: RESULTS FROM LINKING ELECTRONIC HEALTH RECORDS TO PATIENT-REPORTED OUTCOMES	2019	Value in Health	Non-EHR integration
Ignacio, MartÃez; Javier, Escayola; Miguel, MartÃnez-Espronceda; Pilar, MuÃ±oz; JesÃºs Daniel, Trigo; Adolfo, MuÃ±oz; Santiago, Led; Luis, Serrano; JosÃ©, GarcÃa	Seamless Integration of ISO/IEEE11073 Personal Health Devices and ISO/EN13606 Electronic Health Records into an End-to-End Interoperable Solution	2010	Telemedicine & e-Health	Potential to Integrate Only
Jacobs, L. A.; Blauch, A. N.; Pucci, D. A.; De Michele, A.; Palmer, S. C.	Implementing a web-based patient reported outcomes (PRO) assessment: Uptake, usability, and lessons learned	2019	Journal of Clinical Oncology	Insufficient data
Jadczyk, T.; Kiwic, O.; Khandwalla, R. M.; Grabowski, K.; Rudawski, S.; Magaczewski, P.; Benyahia, H.; Wojakowski, W.; Henry, T. D.	Feasibility of a voice-enabled automated platform for medical data collection: CardioCube	2019	International Journal of Medical Informatics	Not Patient Generated Health Data
Jamison, R. N.; Jurcik, D. C.; Edwards, R. R.; Huang, C. C.; Ross, E. L.	A Pilot Comparison of a Smartphone App With or Without 2-Way Messaging Among Chronic Pain Patients: Who Benefits From a Pain App?	2017	Clinical Journal of Pain	Non-EHR integration
Jensen, R. E.; Rothrock, N. E.; DeWitt, E. M.; Spiegel, B.; Tucker, C. A.; Crane, H. M.; Forrest, C. B.; Patrick, D. L.; Fredericksen, R.; Shulman, L. M.; Cella, D.; Crane, P. K.	The role of technical advances in the adoption and integration of patient-reported outcomes in clinical care	2015	Medical Care	Wrong study design

Authors	Title	Year	Journal	Exclusion Reason
Johnstone, P. A. S.; Bulls, H. W.; Zhou, J. M.; Lee, J. K.; Portman, D.; Yu, H. M.; Jim, H.	Congruence of multiple patient-related outcomes within a single day	2019	Supportive Care in Cancer	Not PGHD
Joseph, A.; Herrera, D.; Kildea, J.; Hijal, T.; Hendren, L.	Opal-the oncology patient application	2016	Medical Physics	Wrong study design
Juckett, D. A.; Davis, F. N.; Gostine, M.; Reed, P.; Risko, R.	Patient-reported outcomes in a large community-based pain medicine practice: evaluation for use in phenotype modeling	2015	BMC Medical Informatics and Decision Making	Wrong study design
Jung, S. Y.; Kim, J. W.; Hwang, H.; Lee, K.; Baek, R. M.; Lee, H. Y.; Yoo, S.; Song, W.; Han, J. S.	Development of Comprehensive Personal Health Records Integrating Patient-Generated Health Data Directly From Samsung S-Health and Apple Health Apps: Retrospective Cross-Sectional Observational Study	2019	JMIR MHealth and UHealth	Non-EHR integration
Kadambi, V.; Kadambi, N.; Bettgeri, S.; Buddiga, P.; Rajesh, S.; Ramaswami, N.; Hegde, R.	Review of an electronic health record model to facilitate remote patient management in metabolic and lifestyle diseases	2018	Unknown	Wrong study design
Katzan, I. L.; Fan, Y.; Speck, M.; Morton, J.; Fromwiller, L.; Urchek, J.; Uchino, K.; Griffith, S. D.; Modic, M.	Electronic Stroke CarePath: Integrated Approach to Stroke Care	2015	Circulation: Cardiovascular Quality and Outcomes	Not PGHD
Katzan, I.; Speck, M.; Dopler, C.; Urchek, J.; Bielawski, K.; Dunphy, C.; Jehi, L.; Bae, C.; Parchman, A.	The Knowledge Program: an innovative, comprehensive electronic data capture system and warehouse	2011	AMIA ... Annual Symposium Proceedings/AMIA Symposium	Not PGHD
Khan, S.; Usmani, A.	Remote patient monitoring system with a focus on antenatal care for rural population	2014	BJOG: An International Journal of Obstetrics and Gynaecology	Insufficient data
Khan, W. A.; Hussain, M.; Afzal, M.; Amin, M. B.; Lee, S.	Healthcare standards based sensory data exchange for Home Healthcare Monitoring System	2012	2012 Annual International Conference of the IEEE Engineering in Medicine and Biology Society	Wrong study design
Khoshab, N.; Nehal, K. S.; Dusza, S. W.; Lee, E. H.	Determinants of cancer worry in a skin cancer population	2019	Journal of the American Academy of Dermatology	Non-EHR integration
Kidwell, K. M.; Peugh, J.; Westcott, E.; Nwankwo, C.; Britto, M. T.; Quinn, C. T.; Crosby, L. E.	Acceptability and Feasibility of a Disease-specific Patient Portal in Adolescents With Sickle Cell Disease	2019	Journal of Pediatric Hematology/Oncology	Not Patient Generated Health Data
Killeen, J. P.; Chan, T. C.; Castillo, E. M.; Grisworld, W. G.	Integrating environmental data into a personal health record for asthma patients	2015	Annals of Emergency Medicine	Insufficient data
Kim, D. Y.; Hwang, S. H.; Kim, M. G.; Song, J. H.; Lee, S. W.; Kim, I. K.	Development of Parkinson Patient Generated Data Collection Platform Using FHIR and IoT Devices	2017	Studies in Health Technology and Informatics	Non-EHR integration
Koopman, R. J.; Canfield, S. M.; Belden, J. L.; Wegier, P.; Shaffer, V. A.; Valentine, K. D.; Jain, A.; Steege, L. M.; Patil, S. J.; Popescu, M.; LeFevre, M. L.	Home blood pressure data visualization for the management of hypertension: designing for patient and physician information needs	2020	BMC Medical Informatics and Decision Making	Potential to integrate only
Lahiri, M.; Yip, J.	Automated capture and high uptake rates of patient reported outcome measures in routine Rheumatology practice	2019	Annals of the Rheumatic Diseases	Insufficient data
Lapen, K.; Sabol, C.; Lynch, K.; Kassa, A.; Kantor, J.; Cha, E.; Braunstein, L. Z.; Cahlon, O.; Sandler, K.; McCloskey, S. A.; Khan, A. J.; Gillespie, E. F.	Implementation of a Remote Tracking System for Acute Toxicities Using Patient-Reported Outcomes in Patients Treated with Radiation for Breast Cancer	2020	International Journal of Radiation Oncology Biology	Non-EHR integration

Authors	Title	Year	Journal	Exclusion Reason
Leijdekkers, P.; Gay, V.; Demongeot, J.; Geissbuhler, A.; Abdulrazak, B.; Mokhtari, M.; Aloulou, H.	Improving user engagement by aggregating and analysing health and fitness data on a mobile app	2015	Unknown	Potential to Integrate Only
Littlejohn, G. O.; Tymms, K. E.; Smith, T.; Griffiths, H. T.	Using big data from real-world Australian rheumatology encounters to enhance clinical care and research	2020	Clinical and Experimental Rheumatology	Non-EHR integration
Lockner, Julie	The demand for medical devices is growing	2016	Health Management Technology	Wrong study design
Loo, S.; Grasso, C.; Glushkina, J.; McReynolds, J.; Lober, W.; Crane, H.; Mayer, K. H.	Capturing Relevant Patient Data in Clinical Encounters Through Integration of an Electronic Patient-Reported Outcome System Into Routine Primary Care in a Boston Community Health Center: Development and Implementation Study	2020	Journal of Medical Internet Research	Not Patient Generated Health Data
Lv, N.; Xiao, L.; Simmons, M. L.; Rosas, L. G.; Chan, A.; Entwistle, M.	Personalized Hypertension Management Using Patient-Generated Health Data Integrated With Electronic Health Records (EMPOWER-H): Six-Month Pre-Post Study	2017	Journal of Medical Internet Research	EHR to App Integration Only
Mace, Scott	Device Integration With the EHR: Saving Time, Improving Safety	2016	HealthLeaders Magazine	Not PGHD
Macnair, A.; Sharkey, A.; Le Calvez, K.; Walters, R.; Smith, L.; Nelson, A.; Staffurth, J.; Williams, M.; Bloomfield, D.; Maher, J.	The Trigger Project: The Challenge of Introducing Electronic Patient-Reported Outcome Measures Into a Radiotherapy Service	2020	Clinical Oncology	Potential to integrate only
Maldaner, N.; Desai, A.; Gautschi, O. P.; Regli, L.; Ratliff, J. K.; Park, J.; Stienen, M. N.	Improving the patient-physician relationship in the digital era-transformation from subjective questionnaires into objective real-time and patient-specific data reporting tools	2019	Neurospine	Editorial
Maloney, M.	Leveraging Teledermatology for Patient Triage	2019	Journal of the Dermatology Nurses' Association	Not Patient Generated Health Data
Mammen, J. R.; Halterman, J.; Berliant, M. N.; Turgeon, K.; Philibert, A.; Java, J.; Reznik, M.; Feldman, J. M.; Fortuna, R.; Schoonmaker, J. D.; Crowley, A.; Frey, S. M.; Arcoleo, K. J.	Pilot study of an emr-integrated smartphone-telemedicine program as a virtual primary care extension for underserved younger adults with asthma (Teams-Technology Enabled Asthma Management System)	2020	American Journal of Respiratory and Critical Care Medicine	Duplicate
Mammen, J.; Arcoleo, K. J.; Berliant, M.; Costello, A.; Bartock, B.	Process and product: Development of a technology enabled asthma management system (TEAMS) integrating with the epic electronic medical record and real-world clinical practice	2018	American Journal of Respiratory and Critical Care Medicine	Potential to Integrate Only
Mandl, Kenneth D.; Gottlieb, Daniel; Ellis, Alyssa	Beyond One-Off Integrations: A Commercial, Substitutable, Reusable, Standards-Based, Electronic Health Record-Connected App	2019	Journal of Medical Internet Research	Not original article
Mansur, A.; Farooqi, M. H.; Nawaz, S.; Nadeem, N.; Mahmood, A.	MON-107 TELENEPHROLOGY AND REMOTE PATIENT MONITORING AND MANAGEMENT OF CKD 5D PATIENTS	2019	Kidney International Reports	Non-EHR integration
Mantwill, S.; Fiordelli, M.; Ludolph, R.; Schulz, P. J.	EMPOWER-support of patient empowerment by an intelligent self-management pathway for patients: study protocol	2015	BMC Medical Informatics and Decision Making	Potential to Integrate Only
Marceglia, S.; D'Antrassi, P.; Prenassi, M.; Rossi, L.; Barbieri, S.	Point of Care Research: Integrating patient-generated data into electronic health records for clinical trials	2017	AMIA ... Annual Symposium Proceedings/AMIA Symposium	Non-EHR integration
Mare, Shrirang; Sorber, Jacob; Shin, Minho; Cornelius, Cory; Kotz, David	Hide-n-Sense: Preserving Privacy Efficiently in Wireless mHealth	2014	Mobile Networks & Applications	Potential to Integrate Only
McMurtrey, L.; Knitz, D.; Webb, C.; Barger, K.; Cochran, A.; Weeks, H.	Implementation of patient reported outcomes in a burn outpatient clinic	2018	Journal of Burn Care and Research	Insufficient data

Authors	Title	Year	Journal	Exclusion Reason
Mechanic, Oren J.; Kurtzman, Nicholas D.; Chiu, David T.; Nathanson, Larry A.; Berkowitz, Seth J.	Point of Care Image Capture with a Custom Smartphone Application: Experience with an Encounter-Based Workflow	2020	Journal of Digital Imaging	Not Patient Generated Health Data
Michel, J. J.; Fiks, A.; Mayne, S.; Grundmeier, R.; Miller, J.; Broomfield, C.; Hubbard, S.; Power, T.; Pedlar, M.; Bryan, M.; Leavy, S.; Blum, N.; Guevara, J.	A technology driven approach for sharing patient-reported outcomes in ADHD between parents, pediatricians and teachers	2018	Pediatrics	Research study
Milani, R. V.; Lavie, C. J.; Bober, R. M.; Milani, A. R.; Ventura, H. O.	Improving Hypertension Control and Patient Engagement Using Digital Tools	2017	American Journal of Medicine	Insufficient data
Mishuris, R. G.; Yoder, J.; Wilson, D.; Mann, D.	Integrating data from an online diabetes prevention program into an electronic health record and clinical workflow, a design phase usability study	2016	BMC Medical Informatics and Decision Making	Wrong study design
Mooney, K.; Biber, J.; Hess, R.; Weeks, H.; Sweetenham, J. W.	Implementing routine assessment of patient-reported outcomes in cancer care	2017	Journal of Clinical Oncology	Not original article
Morelle, A. M.; De Lima, G. E.; D'Agustini, N.; Venero, F. C.; Barrios, C. H.	Real-time detection of patient-reported outcomes (PRO) through an app: A Brazilian experience	2019	Journal of Clinical Oncology	Insufficient data
Mosmondor, M.; Benc, I.; Desic, S.; Grguric, A.; T. Croatian Telecom; Croatian Electricity, Company; Ericsson Nikola, Tesla; Koncar - Electrical, Industries; Siemens,	A feasibility study for the integration of a remote patient monitoring solution with electronic health record system	2010	Unknown	Wrong study design
Mularski, R. A.; Clark, B.; Pasquale, C.; Gillespie, S. E.; Crawford, P.; Malanga, E.; Malanga, V.; Yawn, B. P.; McBurnie, M.; Davis, K. J.	Validation of a scalable efficient interoperable linkage process for patient-level emr data to patient-reported registration data within the COPD foundation patient powered research network: Building on common pcornet data networks toward a comprehensive COPD research data resource	2018	American Journal of Respiratory and Critical Care Medicine	Not PGHD
Mulder, M.; Den Broeder, A.; Van Ginneken, B.; Mahler, E.; Van Den Hoogen, F.; Vriezekolk, J.; Wenink, M.	Implementing the psoriatic arthritis disease activity score (PASDAS) in routine clinical practice: (IM)possible	2019	Arthritis and Rheumatology	Non-EHR integration
Murali-Ganesh, R.; Tan, Z.; Harvey, A.; Ballurkar, K.; Navani, V.; Pooviah, N.	From smartphone to electronic health record (EHR): An innovative implementation of patient-reported outcomes and patient-generated health data in routine cancer care	2018	Asia-Pacific Journal of Clinical Oncology	Insufficient data
Nagaraja, V.; Ognenovski, V.; Khanna, D.	Use of handheld device to enhance patient reported outcome measure data collection in an academic rheumatology practice	2018	Arthritis and Rheumatology	Wrong study design
Nayak, S.; Hossain, M. A.; Mirza, F.; Naeem, M. A.; Jamil, N.; Costa, A.; Bajwa, I. S.; Kamareddine, F.	E-BRACE: A Secure Electronic Health Record Access Method in Medical Emergency	2019	Unknown	Not PGHD
Neubeck, L.; Coorey, G.; Peiris, D.; Mulley, J.; Heeley, E.; Hersch, F.; Redfern, J.	Development of an integrated e-health tool for people with, or at high risk of, cardiovascular disease: The Consumer Navigation of Electronic Cardiovascular Tools (CONNECT) web application	2016	International Journal of Medical Informatics	EHR to App Integration Only

Authors	Title	Year	Journal	Exclusion Reason
Ognenovski, V.; Burger, K.; Weiss, K.; Esser, L.; Khanna, D.	The feasibility of utilization of mobile devices to enhance patient reported outcomes measures (PROMS) in rheumatology practice	2017	Annals of the Rheumatic Diseases	Non-EHR integration
Oliver, B.; Hall, A.; Messier, R.; Patel, M.; Geremakis, C.	Driving continuous improvement of MS care quality-year one experience and findings from the multiple sclerosis continuous quality improvement (MS-CQI) research collaborative	2019	Neurology	Insufficient data
Olson, L.; Lexvold, N.; Somers, V.; Friedman, P.; Schenck, L.; Lewis, B.; Bruce, C.	Feasibility of remote, non-invasive, wireless, continuous real-time monitoring of heart rate in heart failure patients	2015	Journal of Cardiac Failure	Insufficient data
Ossowski, S.; Kammerer, A.; Basch, E. M.; Katzel, J. A.	Patient-reported outcomes integrated within electronic medical record in patients with head and neck cancer	2020	Journal of Clinical Oncology	Insufficient data
Papuga, M. O.; Dasilva, C.; McIntyre, A.; Mitten, D.; Kates, S.; Baumhauer, J. F.	Large-scale clinical implementation of PROMIS computer adaptive testing with direct incorporation into the electronic medical record	2018	Health Systems	Wrong setting
Patel, K.; Chim, Y. L.; Grant, J.; Wascher, M.; Nathanson, A.; Canfield, S.	Development and Implementation of Clinical Outcome Measures for Automated Collection Within Specialty Pharmacy Practice	2020	Journal of Managed Care and Specialty Pharmacy	Not Patient Generated Health Data
Paterson, M.; McAulay, A.; McKinstry, B.	Integrating third-party telehealth records with the general practice electronic medical record system: a solution	2017	Journal of Innovation in Health Informatics	Not original article
Peeples, M. M.; Iyer, A. K.; Cohen, J. L.	Integration of a mobile-integrated therapy with electronic health records: lessons learned	2013	Journal of Diabetes Science and Technology	Wrong study design
Petrova, Galidiya Ivanova	Patient Data Integration in Electronic Health Record Systems	2014	Annual Journal of Electronics	Wrong study design
Pincus, T.	Electronic multidimensional health assessment questionnaire (eMDHAQ): past, present and future of a proposed single data management system for clinical care, research, quality improvement, and monitoring of long-term outcomes	2016	Clinical and Experimental Rheumatology	Potential to Integrate Only
Pincus, T.; Castrejon, I.; Riad, M.; Obreja, E.; Lewis, C.; Krogh, N. S.	Reliability, Feasibility, and Patient Acceptance of an Electronic Version of a Multidimensional Health Assessment Questionnaire for Routine Rheumatology Care: Validation and Patient Preference Study	2020	JMIR Formative Research	Not Patient Generated Health Data
Pitzen, C.; Larson, J.	Patient-Reported Outcome Measures and Integration Into Electronic Health Records	2016	Journal of Oncology Practice	Wrong study design
Plimpton, E.	A Quality Improvement Project to Increase Patient Portal Enrollment and Utilization in Women Living With HIV at Risk for Disengagement in Care	2020	Journal of Association of Nurses in AIDS Care	Non-EHR integration
Ploner, N.; Prokosch, H. U.	Integrating a Secure and Generic Mobile App for Patient Reported Outcome Acquisition into an EHR Infrastructure Based on FHIR Resources	2020	Studies in Health Technolgy and Informatics	Wrong study design
Ploner, N.; Prokosch, H. U.	Integrating a Secure and Generic Mobile App for Patient Reported Outcome Acquisition into an EHR Infrastructure Based on FHIR Resources...30th Medical Informatics Europe Conference	2020	Studies in Health Technolgy and Informatics	Wrong study design
Polubriaginof, F. C. G.; Parekh, P. K.; Akella, N. R. S.; Stetson, P. D.	Adoption patterns of an electronic patient-reported outcomes tool in oncology	2020	Journal of Clinical Oncology	Wrong study design
Ransom, J.; Shilnikova, A.; Rusli, E.; Ahmed, R.; Galaznik, A.; Lempernesse, B.; Berger, M.	PND98 patterns and prediction for cognitive decline in alzheimer's patients as assessed by the mini-mental status exam in an ambulatory electronic medical record	2019	Value in Health	Not Patient Generated Health Data

Authors	Title	Year	Journal	Exclusion Reason
Redfern, J.; Coorey, G.; Mulley, J.; Scaria, A.; Neubeck, L.; Hafiz, N.; Pitt, C.; Weir, K.; Forbes, J.; Parker, S.; Bampi, F.; Coenen, A.; Enright, G.; Wong, A.; Nguyen, T.; Harris, M.; Zwar, N.; Chow, C. K.; Rodgers, A.; Heeley, E.; Panaretto, K.; Lau, A.; Hayman, N.; Usherwood, T.; Peiris, D.	A digital health intervention for cardiovascular disease management in primary care (CONNECT) randomized controlled trial	2020	Nature Partner Journals	Not Patient Generated Health Data
Redfern, J.; Usherwood, T.; Coorey, G.; Mulley, J.; Scaria, A.; Neubeck, L.; Hafiz, N.; Chow, C.; Peiris, D.	A consumer-direct digital health intervention for cardiovascular risk management in primary care: The Consumer Navigation of Electronic Cardiovascular Tools (CONNECT) randomised controlled trial	2019	European Heart Journal	Research study
Rivera SÃ¡nchez, Y. K.; Demurjian, S. A.; Gnirke, L.; Krempels, K.; Monfort, V.; Majchrzak, T. A.; Traverso, P.	Attaining role-based, mandatory, and discretionary access control for services by Intercepting API Calls in Mobile Systems	2018	Unknown	Non-EHR integration
Rodrigues, J. J.; Pedro, L. M.; Vardasca, T.; de la Torre-Diez, I.; Martins, H. M.	Mobile health platform for pressure ulcer monitoring with electronic health record integration	2013	Health Informatics Journal	Not PGHD
Rodriguez, S.; Hwang, K.; Wang, J.	Connecting Home-Based Self-Monitoring of Blood Pressure Data Into Electronic Health Records for Hypertension Care: A Qualitative Inquiry With Primary Care Providers	2019	JMIR Formative Research	Wrong study design
Rossi, E.; Fontelo, P.; Ackerman, M. J.; Pozzi, G.; Marceglia, S.; Fu, W. T.; Balakrishnan, P.; Harabagiu, S.; Wang, F.; Srivatsava, J.	A prototype of mobile app/EHR communication through standards for home treatment of transcranial direct current stimulation	2015	Unknown	Potential to Integrate Only
Rudin, R. S.; Fanta, C. H.; Predmore, Z.; Kron, K.; Edelen, M. O.; Landman, A. B.; Zimlichman, E.; Bates, D. W.	Core Components for a Clinically Integrated mHealth App for Asthma Symptom Monitoring	2017	Applied Clinical Informatics	Potential to Integrate Only
Ryu, B.; Kim, N.; Heo, E.; Yoo, S.; Lee, K.; Hwang, H.; Kim, J. W.; Kim, Y.; Lee, J.; Jung, S. Y.	Impact of an Electronic Health Record-Integrated Personal Health Record on Patient Participation in Health Care: Development and Randomized Controlled Trial of MyHealthKeeper	2017	Journal of Medical Internet Research	Non-EHR integration
Sargious, A.; Lee, S. J.	Remote collection of questionnaires	2014	Clinical and Experimental Rheumatology	Wrong study design
Saripalle, R. K.	Leveraging FHIR to Integrate Activity Data with Electronic Health Record	2019	Health and Technology	Potential to Integrate Only
Saripalle, R.; Moucek, R.; Fred, A.; Gamboa, H.; Institute for, Systems; Technologies of Information, Control; Communication,	Integrating physical activity data with electronic health record	2019	Unknown	Insufficient data
Sayeed, R.; Gottlieb, D.; Mandl, K. D.	SMART Markers: collecting patient-generated health data as a standardized property of health information technology	2020	Nature Partner Journals	Wrong study design

Authors	Title	Year	Journal	Exclusion Reason
Schoenthaler, A.; Cruz, J.; Payano, L.; Rosado, M.; Labbe, K.; Johnson, C.; Gonzalez, J.; Patxot, M.; Patel, S.; Leven, E.; Mann, D.	Investigation of a Mobile Health Texting Tool for Embedding Patient-Reported Data Into Diabetes Management (i-Matter): Development and Usability Study	2020	JMIR Formative Research	Potential to integrate only
Schuler, M.; Trautmann, F.; Radloff, M.; Hentschel, L.; Petzold, T.; Eberlein-Gonska, M.; Ehninger, G.; Schmitt, J.	Implementation and first results of a tablet-based assessment referring to patient-reported outcomes in an inpatient cancer care unit	2017	Zeitschrift fur Evidenz Fortbildung und Qualitat im Gesundheitswesen	Wrong study design
Scotté, Florian; Minvielle, Etienne; Mir, Olivier; André, Fabrice; Barlesi, Fabrice; Soria, Jean-Charles	A patient reported outcome platform, a useful tool to improve monitoring and effective management of Covid-19–positive patients with cancer	2020	European Journal of Cancer	Non-EHR integration
Secrest, A. M.; Chren, M. M.; Hopkins, Z. H.; Chen, S. C.; Ferris, L. K.; Hess, R.	Benefits to patient care of electronically capturing patient-reported outcomes in dermatology	2019	British Journal of Dermatology	Editorial
Secrest, A. M.; Flint, N. D.; Hess, R.	582 Electronic patient-reported outcome implementation in dermatology	2019	Journal of Investigative Dermatology	Insufficient data
Seo, D.; Park, Y. R.; Lee, Y.; Kim, J. Y.; Park, J. Y.; Lee, J. H.	The Use of Mobile Personal Health Records for Hemoglobin A1c Regulation in Patients With Diabetes: Retrospective Observational Study	2020	Journal of Medical Internet Research	Integrated EHR/EMR data to app
Seppen, B.; L'Ami, M. J.; Rico, S.; Wee, M. T.; Turkstra, F.; Roorda, L. D.; Catarinella, F.; Van Schaardenburg, D.; Nurmohamed, M.; Boers, M.; Bos, W. H.	Development and testing of a smartphone application to self-monitor disease activity in rheumatoid arthritis	2019	Annals of the Rheumatic Diseases	Insufficient data
Shah, N. K.; Gabriel, P. E.; Kim, K.; Anstadt, E. J.; Maxwell, R. J. L.; Davis, E. L.; Garrett, M.; Shulman, L.; Metz, J. M.; Wojcieszynski, A. P.	Implementation of Patient-Reported Outcome Collection in Radiation Oncology Clinics in a Large Healthcare System	2020	nternational Journal of Radiation Oncology Biology Physics	Insufficient data
Shah, N.; Wojcieszynski, A.; Davis, E.; Braun, J.; Garrett, M.; Shulman, L. N.; Metz, J. M.; Gabriel, P. E.	Implementing routine patientreported outcome collection in a large, academic health system	2020	Journal of Clinical Oncology	Duplicate
Sharp, C. A.; Austin, L.; Machin, M.; Humphreys, J.; Mellor, P.; McCarthy, J.; Van Der Veer, S.; Davies, L.; Ainsworth, J.; Sanders, C.; Dixon, W.	Sharing the burden of rheumatoid arthritis through remote monitoring of rheumatoid arthritis (REMORA): Implications for patients and clinicians	2018	Annals of the Rheumatic Diseases	Insufficient data
Shears, A.; Bayman, N.; Harris, M.; Lee, L.; Haslett, K.; Wilson, B.; Faivre-Finn, C.	Electronic patient reported outcomes significantly improved toxicity data collection and were acceptable to both patients and clinicians in lung cancer radiotherapy outpatient clinics	2016	Lung Cancer	Wrong study design
Simon, Gregory E.; Shortreed, Susan M.; Johnson, Eric; Rossom, Rebecca C.; Lynch, Frances L.; Ziebell, Rebecca; Penfold; Robert, B.	What health records data are required for accurate prediction of suicidal behavior?	2019	Journal of the American Medical Informatics Association	Wrong study design
Stoner, B.; Schootman, M.; Shacham, E.; Rother, D.; Presti, R.	Developing and implementing an iPad-based sexual history application to increase extra-genital gonorrhea (GC) and chlamydia (CT) testing in men who have sex with men (MSM)	2014	Sexually Transmitted Diseases	Wrong study design

Authors	Title	Year	Journal	Exclusion Reason
Sztankay, Monika; Neppl, Lucia; Wintner, Lisa M.; Loth, Fanny L.; Willenbacher, Wolfgang; Weger, Roman; Weyrer, Walpurga; Steurer, Michael; Rumpold, Gerhard; Holzner, Bernhard	Complementing clinical cancer registry data with patient reported outcomes: A feasibility study on routine electronic patient-reported outcome assessment for the Austrian Myelome Registry	2019	European Journal of Cancer Care	Non-EHR integration
Taarnhøj, G. A.; Lindberg, H.; Dohn, L. H.; Omland, L. Hø; Hjøllund, N. H.; Johansen, C.; Pappot, H.	Electronic reporting of patient-reported outcomes in a fragile and comorbid population during cancer therapy - A feasibility study	2020	Health and Quality of Life Outcomes	Non-EHR integration
Takpor, T. O.; Atayero, A. A.; Ao, S. I.; Gelman, L.; Korsunsky, A. M.; Ao, S. I.; Hukins, D. W. L.; Hunter, A.; Ao, S. I.; Gelman, L.; Iaeng Society of Artificial Intelligence; Iaeng Society of Bioinformatics; Iaeng Society of Computer Science; Iaeng Society of Data Mining; Iaeng Society of Electrical Engineering; et al.,	Integrating internet of things and EHealth solutions for students' healthcare	2015	Unknown	Wrong study design
Terstriep, S. A.; Wacker, J.; Quinlan, C.; Pochardt, K.; Basch, E. M.	Use of remote symptom monitoring with breast cancer survivors using patient reported outcome measures through Epic Mychart	2019	Journal of Clinical Oncology	Insufficient data
Terstriep, S. A.; Wacker, J.; Quinlan, C.; Pochardt, K.; Basch, E. M.	Use of remote symptom monitoring with breast cancer survivors using patient-reported outcome (PRO) measures in MyChart	2019	Journal of Clinical Oncology	Insufficient data
Van Deen, W. K.; Choi, J. M.; Zand, A.; Ha, C. Y.; Inserra, E. K.; Eimers, L.; Centeno, A.; Roth, B. E.; Cole, D.; Getzug, T.; Kane, E.; Connolly, L. S.; Ovsiowitz, M.; Ho, A. D.; Van Oijen, M. G.; Esrailian, E.; Hommes, D. W.	The development of E-health tools for the management of inflammatory bowel diseases	2014	Gastroenterology	Insufficient data
Van Der Burg, G. J.	13Health in diabetes management-the BLink experience	2013	Pediatric Diabetes	Insufficient data
Van Der Veer, S.; Austin, L.; Sanders, C.; Dixon, W.	Using smartphones to improve remote monitoring of rheumatoid arthritis: Completeness of patients' symptom reports	2017	Annals of the Rheumatic Diseases	Insufficient data
Van der Velde, E. T.; Atsma, D. E.; Foeken, H.; Witteman, T. A.; Hoekstra, W. H.	Remote monitoring of patients with implanted devices: data exchange and integration	2013	European Journal of Preventive Cardiology	Potential to Integrate Only
van der Velde, E. T.; Foeken, H.; Witteman, T. A.; van Erven, L.; Schalij, M. J.	Integration of data from remote monitoring systems and programmers into the hospital electronic health record system based on international standards	2012	Netherlands Heart Journal	Potential to Integrate Only
Varady, Nathan H.; d'Amonville, Suzanne; Chen, Antonia F.; d'Amonville, Suzanne	Electronic Patient Portal Use in Orthopaedic Surgery Is Associated with Disparities, Improved Satisfaction, and Lower No-Show Rates	2020	Journal of Bone & Joint Surgery, American Volume	Wrong outcomes
Vuppalapati, J. S.; Kedari, S.; Ilapakurti, A.; Kedari, S.; Gudivada, M.; Vuppalapati, C.	The role of Voice Service technologies in creating the next generation outpatient data driven Electronic Health Record (EHR)	2018	Unknown	Wrong study design

Authors	Title	Year	Journal	Exclusion Reason
Wagner, L. I.; Schink, J.; Bass, M.; Patel, S.; Diaz, M. V.; Rothrock, N.; Pearman, T.; Gershon, R.; Penedo, F. J.; Rosen, S.; Cella, D.	Bringing PROMIS to practice: brief and precise symptom screening in ambulatory cancer care	2015	Cancer	Wrong setting
Walinjkar, A.; Woods, J.; Liggett, S.; Oram, D.; Vagapov, Y.; Picking, R.; Houlden, N.; Mayers, J.; Cunningham, S.; Grout, V.; Abd-Alhameed, R. A.	Personalized wearable systems for real-Time ECG classification and healthcare interoperability: Real-Time ECG classification and FHIR interoperability	2017	Unknown	Wrong study design
Wang, J.; Chu, C. F.; Li, C.; Hayes, L.; Siminerio, L.	Diabetes Educators' Insights Regarding Connecting Mobile Phone- and Wearable Tracker-Collected Self-Monitoring Information to a Nationally-Used Electronic Health Record System for Diabetes Education: Descriptive Qualitative Study	2018	JMIR MHealth and UHealth	Potential to Integrate Only
Warner, J. L.; Rioth, M. J.; Mandl, K. D.; Mandel, J. C.; Kreda, D. A.; Kohane, I. S.; Carbone, D.; Oreto, R.; Wang, L.; Zhu, S.; Yao, H.; Alterovitz, G.	SMART precision cancer medicine: a FHIR-based app to provide genomic information at the point of care	2016	Journal of the American Medical Informatics Association	Potential to Integrate Only
Weatherly, J.; Kishnani, S. S.; Aye, T.	Automated integration of glucometer data into the electronic health record	2018	Diabetes	Insufficient data
Weatherly, J.; Kishnani, S.; Aye, T.	Challenges with Patient Adoption of Automated Integration of Blood Glucose Meter Data in the Electronic Health Record	2019	Diabetes Technology & Therapeutics	Insufficient data
Webers, C.; Beckers, E.; Boonen, A.; van Eijk-Hustings, Y.; Vonkeman, H.; van de Laar, M.; van Tubergen, A.	Development, usability and acceptability of an integrated eHealth system for spondyloarthritis in the Netherlands (SpA-Net)	2019	RMD Open	Non-EHR integration
Wesley, D. B.; Schubel, L.; Chun-Ju, Hsiao; Burn, S.; Howe, J.; Kellogg, K.; Lincoln, A.; Kim, B.; Ratwani, R.	A socio-technical systems approach to the use of health IT for patient reported outcomes: patient and healthcare provider perspectives	2019	Journal of Biomedical Informatics	Not Patient Generated Health Data
Wickramasinghe, N.; Chalasani, S.; Goldberg, S.; Koritala, S.	The benefits of wireless enabled applications to facilitate superior healthcare delivery: The case of DiaMonD	2012	International Journal of E-Health and Medical Communications	Wrong study design
Wintner, L. M.; Sztankay, M.; Riedl, D.; Rumpold, G.; Nickels, A.; Licht, T.; Holzner, B.	How to implement routine electronic patient-reported outcome monitoring in oncology rehabilitation	2020	International Journal of Clinical Practice	Inpatient setting
Wood, E.; Yang, Q.; Steinberg, D.; Barnes, A.; Vaughn, J.; Vorderstrasse, A.; Crowley, M.; Henriquez, C.; Streicher, M.; Bass Blue, D.; Choi, S.; Shaw, R. J.	Diabetes Mobile Care: Aggregating and Visualizing Data from Multiple Mobile Health Technologies	2019	AMIA Summits on Translational Science Proceedings	Non-EHR integration
Wright, P.; Ashley, L.; Craig, A.; Ingleson, E.; Stark, D.; Kozlowska, K.; Velikova, G.	Clinical applications of the ePOCS system: Preliminary findings, challenges and implications	2013	Psycho-Oncology	Wrong study design
Yang, T.; Li, F.; Zhu, B.; Chen, Y.; Chen, D.; Wang, C.; Hou, Z.; Xu, J.; Gu, S.; Liu, J.; Wu, Z.; Wang, Y.; Jin, C.	An Exploratory Study of the Use of the Electronic Health Records of Hypertensive Patients to Support the Primary Prevention of Stroke in Shanghai	2020	Risk Management and Healthcare Policy	Not Patient Generated Health Data

Authors	Title	Year	Journal	Exclusion Reason
Zao, J. K.; Wang, M. Y.; Tsai, P.; Liu, J. W. S.; Ieee Communication Society	Smart phone based medicine in-take scheduler, reminder and monitor	2010	Unknown	Not PGHD
Zimmerman, K.; May, B.; Barnes, K.; Arynchyna, A.; Alford, E. N.; Arata Wessinger, C.; Dreer, L.; Aban, I.; Johnston, J. M.; Rozzelle, C. J.; Blount, J. P.; Rocque, B. G.	Anxiety, depression, fatigue, and headache burden in the pediatric hydrocephalus population	2020	Journal of neurosurgery. Pediatrics	Non-EHR integration
Zylla, D. M.; Gilmore, G. E.; Steele, G. L.; Eklund, J. P.; Wood, C. M.; Stover, A. M.; Shapiro, A. C.	Collection of electronic patient-reported symptoms in patients with advanced cancer using Epic MyChart surveys	2020	Support Care Cancer	Research study
	Whats new in "connected" medical devices? Physicians and parents are adopting a host of health-related tools that communicate with smartphones and tablets. Here are the latest worth checking out	2015	Contemporary Pediatrics	Wrong study design
	Including Patient-Generated Health Data in Electronic Health Records...Practice Guidelines for Managing Health Information	2015	Journal of AHIMA	Wrong study design
	ePRO: A Maturing and Widely-Preferred Market	2013	Applied Clinical Trials	Not PGHD

Appendix F. Scoping Review Study Characteristics

Table F-1. Scoping review study characteristics

Study	Geographic Region	Study Aim	Study Design	Study Setting	Study Population
Ancker, J. S., Mauer, E., Kalish, R. B., Vest, J. R., & Gossey, J. T. (2019). Early adopters of patient-generated health data upload in an electronic patient portal. *Applied Clinical Informatics, 10*(2), 254–260. doi:10.1055/s-0039-1683987	United States	To describe adoption rates and characteristics of early adopters of PGHD functionality with preliminary data about associations	Observational: Retrospective cohort	Multispecialty faculty practice—physician ambulatory offices and ambulatory hospital-based clinics	12 providers, 53 patients with any recorded diagnosis of diabetes or gestational diabetes
Bachmann, J. M., Posch, D. R., Hickson, G. B., Pinson, C. W., Kripalani, S., Dittus, R. S., Stead, W. W. (2020). Developing an Implementation Strategy for Systematic Measurement of Patient-Reported Outcomes at an Academic Health Center. *Journal of Healthcare Management;65(1):*15-28	United States	To describe the strategy utilized to integrate PROMs in the EHR	Descriptive: System Description	Academic Medical Center	N/A
Bae, Y. S., Kim, K. H., Choi, S. W., Ko, T., Jeong, C. W., Cho, B., … Kang, E. (2020). Information Technology-Based Management of Clinically Healthy COVID-19 Patients: Lessons From a Living and Treatment Support Center Operated by Seoul National University Hospital. *Journal of Medical Internet Research; 22(6):e19938*	Korea	To introduce the experience [in South Korea] implementing information and communications technology (ICT)-based remote patient management systems at a COVID-19 LTSC [living and treatment support center]	Descriptive: System Description	Academic Medical Center	N/A
Bhavnani, S. P., Cohoon, T., Shen, C., Khedraki, R., Hu, S. (2020). From Electronic Medical Record Integration to Reimbursement: Practical Implications of Chronic Care Management Through a Remote Patient Monitoring (CPT 99091) Cardiovascular Program. *Journal of the American College of Cardiology;75(11):3621*	United States	To determine the real-world utilization of RPM in CV practices within a 99091 practice including hypertension, heart failure, and arrhythmia monitoring. Calculate billing and reimbursement to gauge public and private payment coverage.	Observational	Large integrated healthcare center	244 eligible patients with hypertension, congestive heart failure, or an arrhythmia
Bloom, P., Wang, T., Marx, M., Tagerman, M., Green, B., Arvind, A., … Richter, J. M. (2020). A Smartphone App to Manage Cirrhotic Ascites Among Outpatients: Feasibility Study. *JMIR Medical Informatics;8(9):e17770*	United States	To evaluate the feasibility of a smartphone app in facilitating outpatient ascites management	Experimental/Interventional trial (e.g. RCT)	Academic Medical Center	25 cirrhotic patients
Coenen, S., Nijns, E., Weyts, E., Geens, P., Van den Bosch, B., Vermeire, S., … Van Assche, G. (2020). Development and feasibility of a telemonitoring tool with full integration in the electronic medical record: a proof of concept study for patients with inflammatory bowel disease in remission on biological therapy. *Scandinavian Journal of Gastroenterology; 55(3):*287-293	Belgium	To evaluate the implementation and patient use of an IBD mobile app.	Observational	Academic Medical Center	45 IBD patients

Study	Geographic Region	Study Aim	Study Design	Study Setting	Study Population
Day, F. C., Pourhomayoun, M., Keeves, D., Lees, A. F., Sarrafzadeh, M., Bell, D., & Pfeffer, M. A. (2019). Feasibility study of an EHR-integrated mobile shared decision making application. *International Journal of Medical Informatics, 124*, 24–30.	United States	To test the usability of a trial-tested Web-based patient-education intervention into an EHR-integrated mobile application	Observational: Cross- sectional	Single clinic	4 providers, 9 patients being screened for prostate specific antigen
Fisher, N. D., Fera, L. E., Dunning, J. R., Desai, S., Matta, L., Liquori, V., … MacRae, C. A. (2019). Development of an entirely remote, non- physician led hypertension management program. *Clinical Cardiology, 42*(2), 285–291.	United States	To develop a remote, navigator-led, home-based hypertension program	Experimental: Pre/post	Primary care and specialty clinics	130 patients with hypertension
Forshaw-Hulme, S., Oldham, A. (2019). Self-management using wearable technology, to promote knowledge and skill in patients ability to manage their own care. *Physiotherapy (United Kingdom);107():e129-e130*	United Kingdom	To assess the influence of wearable technology in assisting patients in managing their own care.	Observational	Non-profit, non-academic health system	Six patients with Lysosomal Storage Disease
Girgis, A., Durcinoska, I., Arnold, A., & Delaney, G. P. (2019). Interpreting and acting on the PRO scores from the Patient-reported Outcomes for Personalized Treatment and Care (PROMPT- Care) eHealth system. *Medical Care, 57*, S85–S91.	Australia	To detail methods and processes that informed PROMPT-Care program development	(No evaluation)	Four cancer centers	400+ patients in 4 cancer centers
Girgis, A., Durcinoska, I., Arnold, A., Descallar, J., Kaadan, N., Miller, A., … Delaney, G. P. (2019). Web-Based Patient-Reported Outcome Measures for Personalized Treatment and Care (PROMPT-Care): Multicenter Pragmatic Nonrandomized Trial. *Journal of Medical Internet Research ;22(10):e19685*	Australia	To implement the PROMPT-Care (Patient Reported Outcome Measures for Personalized Treatment and Care) web-based system into existing clinical workflows and evaluate its effectiveness among a diverse population of patients with cancer.	Experimental/Interventional trial (e.g. RCT)	Four public hospitals	328 patients in 4 public hospitals
Gold, H. T., Karia, R. J., Link, A., Lebwohl, R., Zuckerman, J. D., Errico, T. J., … Cantor, M. N. (2018). Implementation and early adaptation of patient- reported outcome measures into an electronic health record: A technical report. *Journal of Health and Medical Informatics*. doi:10.1177/1460458218813710	United States	To describe the design and implementation of creating patient-reported outcomes measures	Mixed methods: Cross- sectional, descriptive	Large urban academic medical center, department of orthopedic surgery	58 physicians (36,121 visits)
Graetz, I., Anderson, J. N., McKillop, C. N., Stepanski, E. J., Paladino, A. J., & Tillmanns, T. D. (2018). Use of a Web-based app to improve postoperative outcomes for patients receiving gynecological oncology care: A randomized controlled feasibility trial. *Gynecologic Oncology, 150*(2), 311–317.	United States	To evaluate a postoperative Web-based application intervention to provide real-time symptom monitoring to patients who had open bilateral salpingo-oophorectomy surgery	Experimental: Randomized controlled trial	Cancer center	35 patients diagnosed or with suspected of having gynecological cancer

Study	Geographic Region	Study Aim	Study Design	Study Setting	Study Population
Judson, T. J., Odisho, A. Y., Neinstein, A. B., Chao, J., Williams, A., Miller, C., … Gonzales, R. (2020). Rapid design and implementation of an integrated patient self-triage and self-scheduling tool for COVID-19. *Journal of the American Medical Informatics Association; 27(6):*860-866	United States	To describe the rapid implementation of a self-triage/scheduling tool used for COVID-19	Descriptive	Academic Medical Center	950 patients
Kumar, R. B., Goren, N. D., Stark, D. E., Wall, D. P., & Longhurst, C. A. (2016). Automated integration of continuous glucose monitor data in the electronic health record using consumer technology. *Journal of the American Medical Informatics Association, 23*(3), 532–37. doi:10.1093/jamia/ocv206	United States	To pilot and assess the feasibility of automatic integration of continuous glucose monitor data in the EHR using consumer technology	Descriptive	Clinic setting	1 provider, 10 pediatric patients with insulin-dependent diabetes
Lesko, M. B., Rudym, D., Kon, Z., Chang, S., Lamaina, V., Snodgrass, C., … Angel, L. F. (2020). Telehealth and Home Monitoring in Lung Transplant. *Journal of Heart and Lung Transplantation; 39(4):S383*	United States	To evaluate the hypothesis that home monitoring and telehealth utilizing data from a mobile healthcare application in conjunction with laboratory values and chest imaging, can replace an outpatient appointment	Descriptive: System Description	Academic Medical Center	50 patients who received a single or bilateral lung transplant or a heart/lung transplant
Leventhal, R. (2015). *How Duke is using HealthKit to get patient- generated data into the EHR.* Retrieved from https://www.hcinnovationgroup.com/clinical-it/article/13025001/how-duke-is- using-healthkit-to-get-patient-generated-data-into-the-her	United States	To describe the use of HealthKit to get PGHD into the EHR	(No evaluation)	Outpatient setting	Fewer than 50 patients and providers
Lewinski, A. A., Drake, C., Shaw, R. J., Jackson, G. L., Bosworth, H. B., Oakes, M., … Crowley, M. J. (2019). Bridging the integration gap between patient-generated blood glucose data and electronic health records. *Journal of the American Medical Informatics Association, 26*, 667–672.	United States	To examine the feasibility of delivering a telemedicine intervention using processes for integration of PGHD into the EHR	Qualitative	2 primary care clinics	35 patients with type 2 diabetes
Mammen, J. R., Schoonmaker, J. D., Java, J., Halterman, J., Berliant, M. N., Crowley, A., Reznik, M., … Arcoleo, K. (2020). Going mobile with primary care: smartphone-telemedicine for asthma management in young urban adults (TEAMS). *Journal of Asthma;* 1-13	United States	To evaluate efficacy and acceptability of the Technology Enabled Asthma Management System (TEAMS) smartphone-telemedicine program when implemented in a real-world clinical practice.	Mixed Methods	Academic Medical Center	30 adult patients and 4 providers

Study	Geographic Region	Study Aim	Study Design	Study Setting	Study Population
Marquard, J. L., Garber, L., Saver, B., Amster, B., Kelleher, M., & Preusse, P. (2013). Overcoming challenges integrating patient- generated data into the clinical EHR: Lessons from the CONtrolling Disease Using Inexpensive IT–Hypertension in Diabetes (CONDUIT-HID) Project. *International Journal of Medical Informatics, 82*, 903–910	United States	To remedy technical and procedural challenges before implementing a randomized controlled trial on a low-cost consumer health informatics intervention	Qualitative	Multispecialty medical group	26 patients
May, J. R., Klass, E., Davis, K., Pearman, T., Rittmeyer, S., Kircher, S., Hitsman, B. (2020). Leveraging Patient Reported Outcomes Measurement via the Electronic Health Record to Connect Patients with Cancer to Smoking Cessation Treatment. *International Journal of Environmental Research and Public Health; 17(14): 13*	United States	To describe the integration of an automated PRO for tobacco use screening and linked referral system within the patient portal/EHR	Descriptive	Academic Medical Center	15,318 patients sent screener for smoking within last 30 days
Miyamoto, S., Dharmar, M., Fazio, S., Tang-Feldman, Y., & Young, H. M. (2018). mHealth technology and nurse health coaching to improve health in diabetes: protocol for a randomized controlled trial. *JMIR Research Protocols, 7*(2), e45. doi:10.2196/resprot.9168	United States	To evaluate the impact of a mobile-health-enabled nurse health coaching intervention	Experimental: Randomized controlled trial	Academic health system—primary care clinics	121 patients with Type-2 diabetes
Moore, S. L., Fischer, H. H., Steele, A. W., Durfee, M. J., Ginosar, D., Rice-Peterson, C., … Davidson, A. J. (2014). A mobile health infrastructure to support underserved patients with chronic disease. *Healthcare, 2*(1), 63–68.	United States	To assess the feasibility of integrating a mobile-health infrastructure with the EMR to support patients with chronic disease	Mixed methods: Prospective cohort, qualitative	Two federally qualified health centers	135 patients with diabetes
Paterson, M., McAulay, A., & McKinstry, B. (2017). Integrating third-party telehealth records with the general practice electronic medical record system: A use case approach. *BMJ Health & Care Informatics, 24*(4), 317–322.	Scotland	To describe a method to produce a report of patient-generated data that is available through their EHR	(No evaluation)	Outpatient setting	1,200 patients
Pennic, J. (2017). *Cedars-Sinai partners with Noteworth to integrate patient-generated data with Epic EMR*. Retrieved from https://hitconsultant.net/2017/05/16/cedars-sinai-noteworth-patient-generated-data/#XgzSqEdKiUk	United States	To integrate patient-generated data into clinical decision making	(No evaluation)	Outpatient setting	Patients with hypertension, congestive heart failure, diabetes, and thyroid disorders, and maternal–fetal medicine patients who had high-risk pregnancies and related conditions, such as gestational diabetes

Study	Geographic Region	Study Aim	Study Design	Study Setting	Study Population
Pevnick, J. M., Elad, Y., Masson, L. M., Riggs, R. V., Duncan, R. G. (2020). Patient-Initiated Data: Our Experience with Enabling Patients to Initiate Incorporation of Heart Rate Data into the Electronic Health Record. *Applied Clinical Informatics;11(4):*671-679	United States	To develop a protocol to address millions of unreviewed heart rates, with a goal of balancing the potential benefits of allowing patients to address clinically concerning heart rates with the potential risks of breaching the confidentiality of patients who had not requested review.	Observational	Academic Medical Center	151 patients
Richards, H. S., Blazeby, J. M., Portal, A., Harding, R., Reed, T., Lander, T., … Avery, K. N. L. (2020). A real-time electronic symptom monitoring system for patients after discharge following surgery: A pilot study in cancer- related surgery. *BMC Cancer; 20(1)*	United Kingdom	To: (i) explore participant eligibility and recruitment; (ii) examine participant ePRO symptom-report response rates and data completeness; (iii) examine the frequency of patient-reported symptoms and ePRO system actions; explore patient and clinician perspectives on using the ePRO system; evaluate the technical performance of the ePRO system; (vi) pilot potential outcome measures for use in a future main trial.	Mixed Methods	Academic Medical Center	29 patients who had undergone cancer- related upper gastrointestinal surgery
Rosett, H. A., Herring, K., Ratliff, W., Koontz, B. F., Zafar, Y., LeBlanc, T. W. (2019). Integration of electronic patient reported outcomes into clinical workflows within the Epic electronic medical record. *Journal of Clinical Oncology; 37(31*	United States	To assess the feasibility and utility of integrating electronic patient-reported outcomes into existing EMR and clinical workflows	Pilot study	3 outpatient clinics	161 patients and 3 physicians
Sharp, J. (2018). *Effectiveness of patient generated health data in routine clinical care.* Retrieved from https://www.pchalliance.org/ne ws/effectiveness-patient- generated-health-data-routine-clinical-care	United States	To demonstrate the flow (of data from the patient to the clinician to the researcher.	No evaluation)	Primary care	Patients with type 2 non-insulin- dependent diabetes
Sorondo, B., Allen, A., Bayleran, J., Doore, S., Fathima, S., Sabbagh, I., & Newcomb, L. (2016). Using a patient portal to transmit patient reported health information into the electronic record: Workflow implications and user experience. *eGEMs, 4*(3), Article 12337. doi:10.13063/2327-9214.1237	United States	To implement an integrated self-report screening tool in a patient portal, to assess workflow and the user experience	Observational	Primary care practices, patient-centered medical home	24 providers, 72 active care-coordinated, chronic-condition patients
Wagner, L. I., Schink, J., Bass, M., Patel, S., Diaz, M. V., Rothrock, N., … Rosen, S. (2015). Bringing PROMIS to practice brief and precise symptom screening in ambulatory cancer care. Cancer, 121, 927–934.	United States	To describe a model for implementing PROMIS ePROs into routine cancer care	Mixed methods with three studies: Prospective cohort Pre/post Qualitative	Outpatient setting	636 women with gynecological cancer

Study	Geographic Region	Study Aim	Study Design	Study Setting	Study Population
Weatherly, J., Kishnani, S., Aye, T. (2019). Challenges with patient adoption of automated integration of blood glucose meter data in the electronic health record. *Diabetes Technology and Therapeutics;21(11):* 671-674	United States	To describe how an automatic integration system (AIS) of GM data into the electronic health record (EHR) would impact patient- provider communication	Observational	Academic Medical Center	28 participants including patients with T1D age 5– 20 years, or their parents, at Stanford Children's Health diabetes clinics who used an Apple iPod or iPhone (5s or higher)
Yamada, J., Segovia, S., Simard, S. N., Kouri, A., Gupta, S. (2020). What are the barriers and enablers to using a patient- facing electronic questionnaire for patients with asthma? *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine; 4():18*	Canada	To identify the determinants (barriers and enablers) of patient uptake and completion of a previsit mobile health questionnaire	Qualitative	Academic Medical Center	12 patients with asthma
Yoo, S., Lim, K., Baek, H., Jang, S. K., Hwang, G. Y., Kim, H., Hwang, H. (2020). Developing a mobile epilepsy management application integrated with an electronic health record for effective seizure management. *International Journal of Medical Informatics; 134*	Korea	To develop a mobile epilepsy management application covering crucial factors comprehensively in a user-friendly way	Mixed methods	Academic Medical Center	3 patients with epilepsy and 5 caregivers
Young, H. M., Miyamoto, S., Dharmar, M., Tang-Feldman, Y. (2020). Nurse Coaching and Mobile Health Compared With Usual Care to Improve Diabetes Self-Efficacy for Persons With Type 2 Diabetes: Randomized Controlled Trial. *JMIR Mhealth Uhealth; 8(3):e16665*	United States	To evaluate the effectiveness of a nurse coaching program using motivational interviewing paired with mobile health (mHealth) technology on diabetes self- efficacy and self-management for persons with type 2 diabetes	Experimental/Interventional trial (e.g. RCT)	Academic Medical Center	287 patients with Type II diabetes
Zhang, R., Burgess, E. R., Reddy, M. C., Rothrock, N. E., Bhatt, S., Rasmussen, L. V., … Starren, J. B. (2019). Provider perspectives on the integration of patient-reported outcomes in an electronic health record. *JAMIA Open, 2*(1), 73–80.	United States	To examine how well an EHR-integrated patient-reported-outcomes system fits the needs and clinical workflows of different provider groups	Qualitative	Orthopedic and oncology departments	11 providers

Note. PROMs = patient-reported outcome measures; PGHD = patient-generated health data; EHR = electronic health record.

Appendix G. Scoping Review Integration Characteristics

Table G-1. Scoping review integration characteristics

Study	PGHD Type	EHR Vendor	Mode of Transfer	Developer Platform	Technical Approach
Ancker, J. S., Mauer, E., Kalish, R. B., Vest, J. R., & Gossey, J. T. (2019). Early adopters of patient-generated health data upload in an electronic patient portal. *Applied Clinical Informatics, 10*(2), 254–260. doi:10.1055/s-0039-1683987	Blood glucose values, insulin dose, time of insulin administration, free-text notes.	Epic	Active; can upload several values per day.	Apple HealthKit ability was enabled	Not reported
Bachmann, J. M., Posch, D. R., Hickson, G. B., Pinson, C. W., Kripalani, S., Dittus, R. S., Stead, W. W. (2020). Developing an Implementation Strategy for Systematic Measurement of Patient-Reported Outcomes at an Academic Health Center. *Journal of Healthcare Management;65(1):*15-28	PRO/survey – Harvey-Bradshaw Index and the Short Inflammatory Bowel Disease Questionnaire, Expanded Prostate Cancer Index Composite, and Asthma Control Test	Epic	Active	Epic Mychart and Welcome	Not applicable
Bae, Y. S., Kim, K. H., Choi, S. W., Ko, T., Jeong, C. W., Cho, B., … Kang, E. (2020). Information Technology-Based Management of Clinically Healthy COVID-19 Patients: Lessons From a Living and Treatment Support Center Operated by Seoul National University Hospital. *Journal of Medical Internet Research; 22(6):e19938*	Biometric and survey based – Patient self- measured vital signs or Vital-sign Data Recorder (VDR-1000)	BEST Care 2.0	Passive	HealthConnect	Not reported
Bhavnani, S. P., Cohoon, T., Shen, C., Khedraki, R., Hu, S. (2020). From Electronic Medical Record Integration to Reimbursement: Practical Implications of Chronic Care Management Through a Remote Patient Monitoring (CPT 99091) Cardiovascular Program. *Journal of the American College of Cardiology;75(11):3621*	Digital devices - BP monitoring, weight monitoring and smartphone ECG	Epic	Both	Apple HealthKit	Not reported
Bloom, P., Wang, T., Marx, M., Tagerman, M., Green, B., Arvind, A., … Richter, J. M. (2020). A Smartphone App to Manage Cirrhotic Ascites Among Outpatients: Feasibility Study. *JMIR Medical Informatics;8(9):e17770*	Biometric – weight A&D UC-352BLE digital scale	Epic	Not reported	PGHD Connect	Not reported

Study	PGHD Type	EHR Vendor	Mode of Transfer	Developer Platform	Technical Approach
Coenen, S., Nijns, E., Weyts, E., Geens, P., Van den Bosch, B., Vermeire, S., … Van Assche, G. (2020). Development and feasibility of a telemonitoring tool with full integration in the electronic medical record: a proof of concept study for patients with inflammatory bowel disease in remission on biological therapy. *Scandinavian Journal of Gastroenterology; 55(3):*287-293	PRO/survey – quality of life evaluated using the 4-item short health scale and work, classroom and activity impairment was collected using the WPAI scale	Not reported	Passive	Mynexuzhealth	Not reported
Day, F. C., Pourhomayoun, M., Keeves, D., Lees, A. F., Sarrafzadeh, M., Bell, D., & Pfeffer, M. A. (2019). Feasibility study of an EHR- integrated mobile shared decision making application. *International Journal of Medical Informatics, 124, 24–30*.	14 data elements: Family history, patient demographics, values, and preferences	Epic	Passive	Not reported.	Seven Epic proprietary non-Fast Healthcare Interoperability Resources Web services
Fisher, N. D., Fera, L. E., Dunning, J. R., Desai, S., Matta, L., Liquori, V., … MacRae, C. A. (2019). Development of an entirely remote, non-physician led hypertension management program. *Clinical Cardiology, 42*(2), 285–291.	Average weekly blood pressures	Not reported	Passive	Unspecified digital platform	Bluetooth enabled blood pressure device
Forshaw-Hulme, S., Oldham, A. (2019). Self-management using wearable technology, to promote knowledge and skill in patients' ability to manage their own care. *Physiotherapy (UK);107():e129-e130*	Biometric – heart rate, blood oxygen, sleep, steps	Allscripts	Active	Validic	Not reported
Girgis, A., Durcinoska, I., Arnold, A., & Delaney, G. P. (2019). Interpreting and acting on the PRO scores from the Patient-reported Outcomes for Personalized Treatment and Care (PROMPT- Care) eHealth system. *Medical Care, 57*, S85–S91.	Electronic patient-reported outcomes	MOSAIQ	Active	PROMPT-Care	Not reported
Girgis, A., Durcinoska, I., Arnold, A., Descallar, J., Kaadan, N., Miller, A., … Delaney, G. P. (2019). Web-Based Patient-Reported Outcome Measures for Personalized Treatment and Care (PROMPT-Care): Multicenter Pragmatic Nonrandomized Trial. *Journal of Medical Internet Research ;22(10):e19685*	PRO/Survey – Distress thermometer checklist, edmonton symptom assessment scale, and supportive care needs survey	MOSAIQ	Passive	Not reported	HL7
Gold, H. T., Karia, R. J., Link, A., Lebwohl, R., Zuckerman, J. D., Errico, T. J., … Cantor, M. N. (2018). Implementation and early adaptation of patient-reported outcome measures into an electronic health record: A technical report. *Journal of Health and Medical Informatics*. doi:10.1177/1460458218813710	PROMIS physical function, pain interference, pain intensity measures, and EuroQol 5D	Epic	Active	Northwestern Medicine patient-reported outcomes system	API for PROMIS CAT from Northwestern University

Study	PGHD Type	EHR Vendor	Mode of Transfer	Developer Platform	Technical Approach
Graetz, I., Anderson, J. N., McKillop, C. N., Stepanski, E. J., Paladino, A. J., & Tillmanns, T.D. (2018). Use of a Web-based app to improve postoperative outcomes for patients receiving gynecological oncology care: A randomized controlled feasibility trial. *Gynecologic Oncology, 150*(2), 311–317.	Treatment side effects, physical and emotional symptoms, and functional status	Not reported	Active	Patient Care Monitor platform	Not reported
Judson, T. J., Odisho, A. Y., Neinstein, A. B., Chao, J., Williams, A., Miller, C., … Gonzales, R. (2020). Rapid design and implementation of an integrated patient self-triage and self- scheduling tool for COVID-19. *Journal of the American Medical Informatics Association; 27(6):*860-866	PRO/Survey – self-triage and self-scheduling tool with high sensitivity for identifying severe disease, and high specificity when recommending self- care. Includes: exposures, symptoms, and comorbidities	Epic	Passive	Epic Toolkit	Not reported
Kumar, R. B., Goren, N. D., Stark, D. E., Wall, D. P., & Longhurst, C. A. (2016). Automated integration of continuous glucose monitor data in the electronic health record using consumer technology. *Journal of the American Medical Informatics Association, 23*(3), 532–537. doi:10.1093/jamia/ocv206	Glucose values (concentration and trend) obtained by interstitial glucose sensor	Epic	Passive	Apple HealthKit	Publicly available custom Web service, one-time Bluetooth pairing.
Lesko, M. B., Rudym, D., Kon, Z., Chang, S., Lamaina, V., Snodgrass, C., … Angel, L. F. (2020). Telehealth and Home Monitoring in Lung Transplant. *Journal of Heart and Lung Transplantation; 39(4):S383*	Biometric – blood pressure, blood oxygen, steps, weight, and temperature	Epic	Both	Unknown app	Not reported
Leventhal, R. (2015). *How Duke is using HealthKit to get patient-generated data into the EHR*. Retrieved from https://www.hcinnovationgroup.com/clinical-it/article/13025001/how-duke-is-using-healthkit-to-get-patientgenerated-data-into-the-ehr	Activity trackers, blood pressure devices, glucose monitoring	Epic	Passive	Apple HealthKit	SMART on Fast Healthcare Interoperability Resources
Lewinski, A. A., Drake, C., Shaw, R. J., Jackson, G. L., Bosworth, H. B., Oakes, M., … Crowley, M. J. (2019). Bridging the integration gap between patient-generated blood glucose data and electronic health records. *Journal of the American Medical Informatics Association, 26*, 667–672.	Blood glucose values	Epic	Active and passive	Apple HealthKit	Bluetooth

Study	PGHD Type	EHR Vendor	Mode of Transfer	Developer Platform	Technical Approach
Mammen, J. R., Schoonmaker, J. D., Java, J., Halterman, J., Berliant, M. N., Crowley, A., Reznik, M., … Arcoleo, K. (2020). Going mobile with primary care: smartphone- telemedicine for asthma management in young urban adults (TEAMS). *Journal of Asthma;* 1-13	Baseline asthma information assessed using smartphone surveys and chart review. Asthma severity assessed by frequency of symptoms, nocturnal awakening, activity limitations, and short acting beta-agonist (SABA) use, using EPR3 criteria	Epic	Both	Technology Enabled Asthma Management System (TEAMS)	Not reported
Marquard, J. L., Garber, L., Saver, B., Amster, B., Kelleher, M., & Preusse, P. (2013). Overcoming challenges integrating patient-generated data into the clinical EHR: Lessons from the CONtrolling Disease Using Inexpensive IT – Hypertension in Diabetes (CONDUIT-HID) Project. *International Journal of Medical Informatics, 82*, 903–910.	Blood pressure	Epic	Active	Healthvault	Health Level 7 Observation Reporting Interface
May, J. R., Klass, E., Davis, K., Pearman, T., Rittmeyer, S., Kircher, S., Hitsman, B. (2020). Leveraging Patient Reported Outcomes Measurement via the Electronic Health Record to Connect Patients with Cancer to Smoking Cessation Treatment. *International Journal of Environmental Research and Public Health;17(14):13*	PRO/Survey – 5-item tobacco screener	Epic	Passive	Epic (in MyChart)	Not reported
Miyamoto, S., Dharmar, M., Fazio, S., Tang- Feldman, Y., & Young, H. M. (2018). mHealth technology and nurse health coaching to improve health in diabetes: protocol for a randomized controlled trial. *JMIR Research Protocols, 7*(2), e45. doi:10.2196/resprot.9168	Physical activity, sleep, and nutrition data	Epic	Passive	Apple HealthKit	Not reported
Moore, S. L., Fischer, H. H., Steele, A. W., Durfee, M. J., Ginosar, D., Rice-Peterson, C., … Davidson, A. J. (2014). A mobile health infrastructure to support underserved patients with chronic disease. *Healthcare, 2*(1), 63–68.	Blood sugar, step counts, blood pressure	Not reported	Active	Patient Relationship Management Software Platform	Not reported
Paterson, M., McAulay, A., & McKinstry, B. (2017). Integrating third-party telehealth records with the general practice electronic medical record system: A use case approach. *BMJ Health & Care Informatics, 24*(4), 317–322.	Blood pressure measurements	Not reported	Active	Intersystems Ensemble	Indicate no API available

Study	PGHD Type	EHR Vendor	Mode of Transfer	Developer Platform	Technical Approach
Pennic, J. (2017). *Cedars-Sinai partners with Noteworth to integrate patient-generated data with Epic EMR*. Retrieved from https://hitconsultant.net/2017/05/16/cedars-%20sinai-noteworth-%20Patient-generated-%20data/#.XgzSqEdKiUk	Blood pressure, blood glucose level, weight, etc., and behavioral data, medication adherence, mood, activity, etc.	Epic	Passive	Not reported	Not reported
Pevnick, J. M., Elad, Y., Masson, L. M., Riggs, R. V., Duncan, R. G. (2020). Patient-Initiated Data: Our Experience with Enabling Patients to Initiate Incorporation of Heart Rate Data into the Electronic Health Record. *Applied Clinical Informatics;11(4)*:671-679	Biometric – heartrate and steps	Epic	Passive	Apple HealthKit	Not reported
Richards, H. S., Blazeby, J. M., Portal, A., Harding, R., Reed, T., Lander, T., … Avery, K. N. L. (2020). A real-time electronic symptom monitoring system for patients after discharge following surgery: A pilot study in cancer- related surgery. *BMC Cancer; 20(1)*	PRO/Survey	Not reported	Active	QTool be X-lab	Custom approach - QStore, was developed to access the QTool. QStore developed using SP.NET MVC and SQL Server
Rosett, H. A., Herring, K., Ratliff, W., Koontz, B. F., Zafar, Y., LeBlanc, T. W. (2019). Integration of electronic patient reported outcomes into clinical workflows within the Epic electronic medical record. *Journal of Clinical Oncology; 37(31)*	PRO/Survey - 10 question Edmonton Symptom Assessment Scale available through the MyChart interface	Epic	Passive	Used built in PRO tool within EPIC	Not reported
Sharp, J. (2018). *Effectiveness of patient generated health data in routine clinical care*. Retrieved from https://www.pchalliance.org/news/effectiveness-%20patient-generated-health-data-routine-clinical-%20care	Blood glucose values	Epic	Passive	Validic	Bluetooth-enabled glucometer
Sorondo, B., Allen, A., Bayleran, J., Doore, S., Fathima, S., Sabbagh, I., & Newcomb, L. (2016). Using a patient portal to transmit patient reported health information into the electronic record: Workflow implications and user experience. *eGEMs, 4*(3), Article 12337. doi:10.13063/2327-9214.1237	Wellness questionnaire survey	GE Centricity	Active	Not reported	Not reported
Wagner, L. I., Schink, J., Bass, M., Patel, S., Diaz, M. V., Rothrock, N., … Rosen, S. (2015). Bringing PROMIS to practice: Brief and precise symptom screening in ambulatory cancer care. *Cancer, 121*, 927–934.	Survey questions: Fatigue, pain interference, physical function, depression, and anxiety	Epic	Active	Not reported	Health Level 7

Study	PGHD Type	EHR Vendor	Mode of Transfer	Developer Platform	Technical Approach
Weatherly, J., Kishnani, S., Aye, T. (2019). Challenges with patient adoption of automated integration of blood glucose meter data in the electronic health record. *Diabetes Technology and Therapeutics;21(11):* 671-674	Biometric – glucose readings	Epic	Passive	Apple HealthKit	Not reported
Yamada, J., Segovia, S., Simard, S. N., Kouri, A., Gupta, S. (2020). What are the barriers and enablers to using a patient-facing electronic questionnaire for patients with asthma? *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine; 4():18*	PRO/Survey – guideline-based asthma control levels	Not reported	Not reported	Not reported	Not reported
Yoo, S., Lim, K., Baek, H., Jang, S. K., Hwang, G. Y., Kim, H., Hwang, H. (2020). Developing a mobile epilepsy management application integrated with an electronic health record for effective seizure management. *International Journal of Medical Informatics; 134*	PRO/Survey – seizure diary, medication diary, education, emotion management, test results, self-survey tools, steps, and sleep data	Unique HER for hospital	Both	Apple HealthKit and FitBit API	HL7 FHIR
Young, H. M., Miyamoto, S., Dharmar, M., Tang-Feldman, Y. (2020). Nurse Coaching and Mobile Health Compared With Usual Care to Improve Diabetes Self-Efficacy for Persons With Type 2 Diabetes: Randomized Controlled Trial. *JMIR Mhealth Uhealth; 8(3):e16665*	Biometric – heart rate, sleep, steps, distance walked, and active minutes	Epic	Passive	Apple HealthKit and MyChart	Not reported
Zhang, R., Burgess, E. R., Reddy, M. C., Rothrock, N. E., Bhatt, S., Rasmussen, L. V., … Starren, J. B. (2019). Provider perspectives on the integration of patient-reported outcomes in an electronic health record. *JAMIA Open, 2*(1), 73– 80.	PROMIS CATs survey questions: Pain interference, physical function, social function, pain- intensity short form, fatigue, depression, anxiety	Epic	Active	Northwestern Medicine patient-reported outcomes system	Not reported

API = application programming interface, EHR = electronic health record, PGHD = patient-generated health data, SMART = substitutable medical applications and reusable technologies